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ABSTRACT

This student manual, part of the Family and Community Health Through Caregiving program, focuses on the special needs of teenagers with birth defects. Topics include: (1) the effect of informal contacts with the community, neighbors, and school age peers on the special needs adolescent; (2) society's attempts to meet these needs; (3) problems of and resources available to adolescent parents of special needs children; and (4) ways that students can help community members with special needs. (CJ)

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Starting A Healthy Family Series/ Family And Community Health Through Caregiving

Families And Futures: Helping Self And Others

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We have come to realize that the quest for quality of life at birth is by its very nature a matrix of science and society.

-- Elaine Whitelaw
Vice President
National Foundation/
March of Dimes

John McGannon

There are a number of efforts that have gone on throughout the length and breadth of the United States in order to talk about the quality of life of our people. And every time we start doing this, one thing becomes very clear: the loss in human fulfillment, the loss in human potential, is extremely great. This is occurring at a rate that is much faster than we can keep up with as a nation, and much faster than we can tolerate if we are to continue as a great nation in the truest sense of that word. For without fulfilled people, how can we consider ourselves a fulfilled society?

In 1970, the American Medical Association began looking at this problem from a medical point of view. We knew that people were coming to physicians in massive numbers, and that these numbers were increasing each year despite our advances in diagnosis, treatment, and cures. What became clear as we looked at the problem was that people were coming to physicians not because of viruses, bacteria, and metabolic problems; not because of lesions in specific organs. Rather, people were seeking help because of their inability to cope, because of problems in their life style, because of problems in their orderly growth and development.

This meant, then, that we had to take a good look at what we mean by health and health care. While medical care is an extremely important part of health care, health is much more than medical care alone. Health means the positive participation of an individual in all the various environments that surround him or her — the physical, social, psychological, and financial conditions in which a person is born and through which a person proceeds with the continuum of his or her life. We must, therefore, place health care within a social, environmental, and educational frame of reference in order to feel that we are developing a sound program of health care. Professionals whose efforts have been fragmented and whose expertise has obeyed strict and traditional boundaries *must work together.* This includes physicians, educators, social scientists, and all others in the human service field, as well as the people they are privileged to serve. No matter what else we are doing, our overriding objective, whether stated or hidden, should be to improve the *quality of life* of our people. To put it another way, we should constantly strive to promote the total human condition of our people.

To achieve this, we must look at the subject in total. We must place each person in the framework of the quality of his life in its many aspects. We must realize that in order to talk about having generation after generation born healthy and living healthy lives, we have to start from the very beginning by thinking of life as a continuum. We must realize that this is a multigenerational issue, that the quality of life of a baby begins with the birth of its parents and continues to influence the quality of life of those who come long after this new person has himself ended his own journey through life. Perhaps most importantly, we must realize that each successful newborn baby presents himself essentially by saying to us, "Here I am, a member of the family of man. What now?" The answer to that question is up to you. It is up to all of us.

Effie O. Ellis, M.D.
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Family and Community Health Through Caregiving is a new kind of health education program that views health with a fresh perspective: health means more than biologic fitness. It is a "measure of each person's ability to do what he wants to do and become what he wants to become."*

Good health results from the decisions we make, decisions that ideally promote our physical, emotional, and social well-being, and connect us to our families and communities in healthy ways.

One goal of this series of books is to encourage people to plan for the future by making choices that improve chances for a satisfying and healthy life.

To make decisions that have positive health results, we must understand:

- why we act in the ways we do.
- how our families and communities can influence and support us.
- how we can make decisions that are right for us by looking at alternatives and their consequences, and then planning wisely.

We have a better chance of making healthy choices when we have thought through our own behaviors carefully.

*Rene Dubos, "Health and Creative Adaptation," *Human Nature*, January 1978, p. 74.

Families and Futures: Helping Self and Others looks both at the ways communities and individuals can help children with special needs and their families and at the steps parents can take before and during pregnancy to provide a healthy and safe environment for their child.

But this is only part of the story. Two other books, *Starting A Healthy Family: Choosing Parenthood*, and *Families With Special-Needs Children* provide other perspectives on the rewards and responsibilities of parents. *Starting A Healthy Family: Choosing Parenthood* explores the choices and life changes that people face when becoming parents or deciding whether and when to become parents. It includes information on prenatal development, the first nine months of life. In *Families With Special-Needs Children*, parents of children with birth defects talk openly about the pain, frustration, and burdens they faced, the rewards they discovered in raising children with special needs, and the resources they found or did not find in themselves and others for coping with their new responsibilities. The causes of birth defects and how inheritance works are explained, to help you understand both the risks involved and ways to prevent birth defects.

A glossary is provided with this book. Reading straight through it will tell you a great deal about parenting and pregnancy, and help you to know what information anyone should have who is thinking about becoming a parent.

Beginnings: Helping Yourself And Others

2

The way we perceive ourselves and others greatly influences our mental and physical health. Human beings are social creatures who rely on others; we value independence, but we recognize that people need each other. It feels good to know you're the kind of person who can give help, and it's healthy to be able to accept it. In giving and accepting help, we learn more about our own needs and about the necessity for constant interplay between people.

There are many ways of helping. In this section, we look at some of the ways families who have children with special needs have been able to help themselves and to accept help from others. We also examine what a person with special needs has to say about his own needs, and how he would like to be treated. And we consider how we can be healthy and start healthy families.

As you read the following case studies, consider the ways in which you might be able to help families in these situations.

Students With Special Needs In Regular Classrooms

For many years special-needs children, if they were considered educable at all, were segregated into special classes in regular schools or placed in completely separate public school settings. Some children were simply ignored by the educational system; considered uneducable, no provisions for their education were made. In recent years, many people have fought against separate education for these children, believing they are entitled by law to exactly the same public education that other children receive.

In 1975, the U.S. Congress passed a law that directed the states to provide full educational opportunities for *every* special-needs child to the age of 21. The law stipulated that to the fullest extent possible special-needs children would be educated in classes with normal children. In some states, this movement has been called "mainstreaming." You may have seen this change come about in your own school system to some degree in the past few years.

In the following case study, the teacher of a 17-year-old special-needs student tells about the experience of this student who has, for the first time in his life, attended regular classes in the public high school in his community.

In some instances, the photos do not represent the actual people in the case studies. This has been done to protect the identity of those wishing to remain anonymous.

Courtesy of WORKSHOP FILMS/SEE

CASE STUDY

1

Stephen Slater

"Sometimes I just don't know where I'm supposed to be."

Stephen Slater was a low birthweight baby. He is mentally retarded, but educable. The teacher of this 17-year-old special-needs student tells about Steve, who is, for the first time in his life, attending regular classes in the public high school in his community.

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Stephen Slater is 17. It would be hard to pick him out from any of the other senior boys in his class. He is just under six feet tall, muscular, and has dark brown eyes and hair that he keeps carefully brushed over his ears. During the past year he has begun to pay closer attention to how he dresses, and he does all his own shopping. On an average day at school, you might see him wearing a faded but well-pressed pair of Levis, a blue button-down shirt, and a ski sweater. Last year he used his savings to pay for a ski trip to Utah, sponsored by a local sports club. He says it was "just terrific, the best time I've ever had."

In one way, Stephen is different from other students on the trip and at his high school; he is mentally retarded.

Stephen's parents learned of their son's retardation just two hours after he was born. The delivering doctor warned them it would be impossible to know the extent of the damage for many years. "It's not severe," he reassured them. "You may never be able to tell anything is wrong with your son by looking at him."

"When Stevie was a baby, even the other mothers on the block admitted he was the cutest," his mother remembers fondly. In many ways, though, it was painfully clear to Stephen's parents that he was slow to develop.

"I learned not to pay attention to those charts in baby books," says his mother. "He would eventually be able to do most anything that other kids could. It would just take him longer. He didn't talk much at all until he was two, and then it was just a few words. He couldn't walk by himself until just before he turned three, and simple things like tying his shoes just took him so long. I thought he might always have to wear loafers, if we were ever able to have him dress by himself."

Stephen was enrolled in a public school, but was kept back in first grade. It was then, after a great deal of deliberation, that his parents enrolled him in a private school with children who, like him, were diagnosed as being mildly to moderately retarded. In the seventh grade, Stephen began attending a special public school for the retarded that had been set up for children in his community and three surrounding towns. For the last two years he has been mainstreamed into the public high school in his community. A counselor meets with him once a week to help him with the problems he is facing.

Some of Stephen's problems are typical for all adolescents; others are more special. There are some things Stephen will never be able to learn. His reading has been on a fifth-grade level for the last three years. Despite specialized tutors and new approaches, he seems unable to make any progress in this area. He still can't understand fractions. "They just don't make any sense to me. I don't get it."

Stephen's I.Q. is 80. An average student might have an I.Q. of 100 to 110; a gifted student might score 120 or higher. This I.Q. score, combined with other test results, gives Stephen's teachers an indication of his capabilities. The teachers are understanding about his learning limitations. It is in other areas that he is having real problems.

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"I don't have a lot of friends," Stephen confides. "I mean, kids are nice to me and all. I can remember some from classes and sometimes their names. We might say 'hi' to each other in the halls. But it's not like I get invitations to, you know, go over to their houses and listen to records or to a party or that stuff."

When he was attending special schools, Stephen had friends with limitations similar to his own. He visited them after school and during the weekends. But now they are in other schools and have drifted away.

"When I'm done with my classes, I usually hang around a while and watch the girls," Stephen admits, laughing. "Then I go home, make a sandwich, and watch TV."

Aside from school, television is Stephen's main activity. He turns it on as soon as he arrives home, takes a break for dinner with his family, and then continues to watch until bedtime. His parents worry about this.

"I wish he'd go out more, get outside the house and hang out with some guys his own age, shoot baskets, drive around — what the hell — even drink a few beers with them on Saturday night," says his father somewhat wistfully. "If only he had just a little more self-confidence. He's a good-looking kid, not that bad an athlete. He could hold up his own in a neighborhood game of touch football. It's just not right, him shutting himself away with that tube all the time."

John McGannon

"Steve does have one friend, Paul," says his mother. "He's a real nice boy. They've known each other since second grade. Sometimes Steve will stop by his house, but that's really it. I've tried to help. I've asked him if he wants to have a party, invite some kids over. I'd be glad to do anything, but he just doesn't seem to know how to go about it. And look, I'm not kidding myself. He is different from the rest of them. I know it. He knows it, too."

Unlike many of his classmates, Stephen will not be going to college. An uncle with a small construction business has promised him a job when he graduates. Stephen is not sure how he feels about that. "It's going to be hard work, I guess. A lot of digging and stuff. In the winter when there's not much building, Uncle Bill said I could help out some in the office — do some filing and addressing mail. I don't know. It's a good job. I'll be making good money. And jobs are hard to find."

But what about being more on his own, being expected to be more independent? "I want to get my regular license and maybe, you know, get my own car. It's a little scary now, driving down really big roads and all."

For a year Stephen has had his temporary license and drives around the neighborhood with his father, but his parents have not encouraged him to get a permanent license. "He needs more time," says his mother. "Give him a few years more. It's just like when he was little. It takes Stevie longer to learn things."

In many ways, he still is "Stevie" to the members of his family. An older sister, Elizabeth, is 28 and lives with her husband and two children in Connecticut. "It's hard to remember that Stevie is almost legally an adult now," she says. "Soon he'll be able to vote, but when he comes visiting and he's playing with my kids, it's almost like he's one of them."

"I worry about what will happen when we're gone," says Mrs. Slater. "It's just too much to expect Elizabeth to have Stevie live with her. She has her own family, her own life. But what else really is there? He's too used to things to be in an institution. He's not that kind of kid. But to think of him living at his own place — I just don't know. I worry about things like whether he'll remember to turn off a gas oven. I've heard of some group homes where people with some of Stevie's handicaps live together with supervision. But I won't have him stuck away."

What is not mentioned by Stephen's parents is the issue of marriage and children. He talks about girls haltingly: "One neat thing about this school I'm in now, there are lots of really pretty girls. You know, it would be so neat to go out with them." He giggles nervously. "I'd like to have a girlfriend, just like the other guys do. And not just for — well, you know — making out and stuff like that." He blushes for a moment before continuing. "But to be able to talk to and go places and do stuff with."

A fulfilling social life seems impossible for Stephen at the high school, where he often appears lost. It pleases him to be recognized and waved to by casual acquaintances, but outside as he waits for the bus to take him home, he looks puzzled.

"Sometimes I like it here and sometimes I don't," he says. "It was nice at my old school. There was more stuff to do. More stuff I could do. And I had more friends. Here, it's neat, people are cooler, more with it. You know, it feels good for me to be going to a regular school, a real school just like everybody else. But sometimes I still get all mixed up. I just don't know where I'm supposed to be."

Guidance Counselor's Notes:

Meeting: Steve Slater's Mother
Subject: Steve Slater
Date: 4/23

Mrs. Slater called me yesterday and urgently requested this meeting. She said that there had been an "emergency" in the family, and she was willing to accept an eight o'clock appointment this morning. When she entered my office, she appeared anxious; her eyes were red as if she'd been crying. Her brother-in-law had had a heart attack last week and died suddenly. The funeral took place over the weekend.

Mrs. Slater was naturally concerned about her brother-in-law's death and the implications of it for her own family as well as his. It had been assumed that her son, Steve, would be working for his uncle's construction firm after he graduated. Now it seems that the business will have to be sold and this will not be possible.

"What will happen to Stevie?" Mrs. Slater asked me. "What else can he do?" I asked her if she had discussed her fears with her husband yet, but she told me that he's still too upset over his brother's death to deal with it.

I was as supportive as possible with Mrs. Slater, agreed that this was hard news, that all of us would have to sit down, separately and together, and reevaluate the situation.

Steve graduates in just four months, so there is not much time left for planning. Meetings will have to be set up with the State Rehabilitation Agency and organizations such as Goodwill. We'll have to concentrate our efforts on a thorough evaluation of Steve's skills and determine what he's capable of doing. It's going to be difficult for the Slaters to face up to some of the facts they'll have to in the next few months. They're going to be visiting workshops, rehab centers, and institutions that they might find threatening and discouraging. I'll have to schedule extra meetings with Steve. He must be frightened about what's happened, and be especially uncertain about things now. It'll be important to give him more of a chance to talk about this.

CASE STUDY

2

Mark Motta

"And the best thing you can do is just to stay there and work with the kid and help him."

Mark Motta, now 20, was born with cerebral palsy. He now resides and works in a sheltered workshop in his community. But he grew up on Oakdale Avenue with his parents and younger sister, Debbie. There they became friendly with Ann and John Senatore and their children, John Roy and David. The interaction of all the people in these two families over the years has been a profound experience for each of them, and others in the community in which they live.

Mark Is Born
by Carolyn Motta

I was 18 when Mark was born prematurely. He weighed two pounds, fifteen ounces and went down to two pounds, eight ounces. He lived in an incubator for two months.

I didn't find out he had cerebral palsy until he was 21 months old. My first reaction was fear. My husband dealt with the news differently. He's a very closed person, and not the kind who is going to start beating his chest and saying, "Oh, my God, why did it happen to us?" He's the type that accepts things. I'm the one who will make the best of things, but that's not saying I'm able to accept the situation.

When Mark was about two, I took him to a hospital to be evaluated. A team of doctors, interns, and residents were around the bed and Mark was screaming. He never stopped screaming at this time. We had been at the hospital all afternoon, and it was about 5:30 when one of the doctors said to me, "Mrs. Motta, I must tell you — if I were you — I'd put this child away in an institution, and forget you ever had him. I looked at the doctor; I couldn't talk. I knew if I opened my mouth I would have cried. The doctor continued: "He'll never walk, he'll never talk, he'll never think, so just put him away and save yourself a lot of grief."

I'll never forget that. It made me mad and I said, "No, it's not true, it's not true."

I knew Mark would probably never get along by himself in today's society. If I'd made that really important, I would have been banging my head against a wall. The point was for us to accept him as much as possible and treat him as normally as possible so he'd get along okay. It wasn't my feelings that were important, it was how he would cope with things.

Betsy Cole

Carolyn Motta

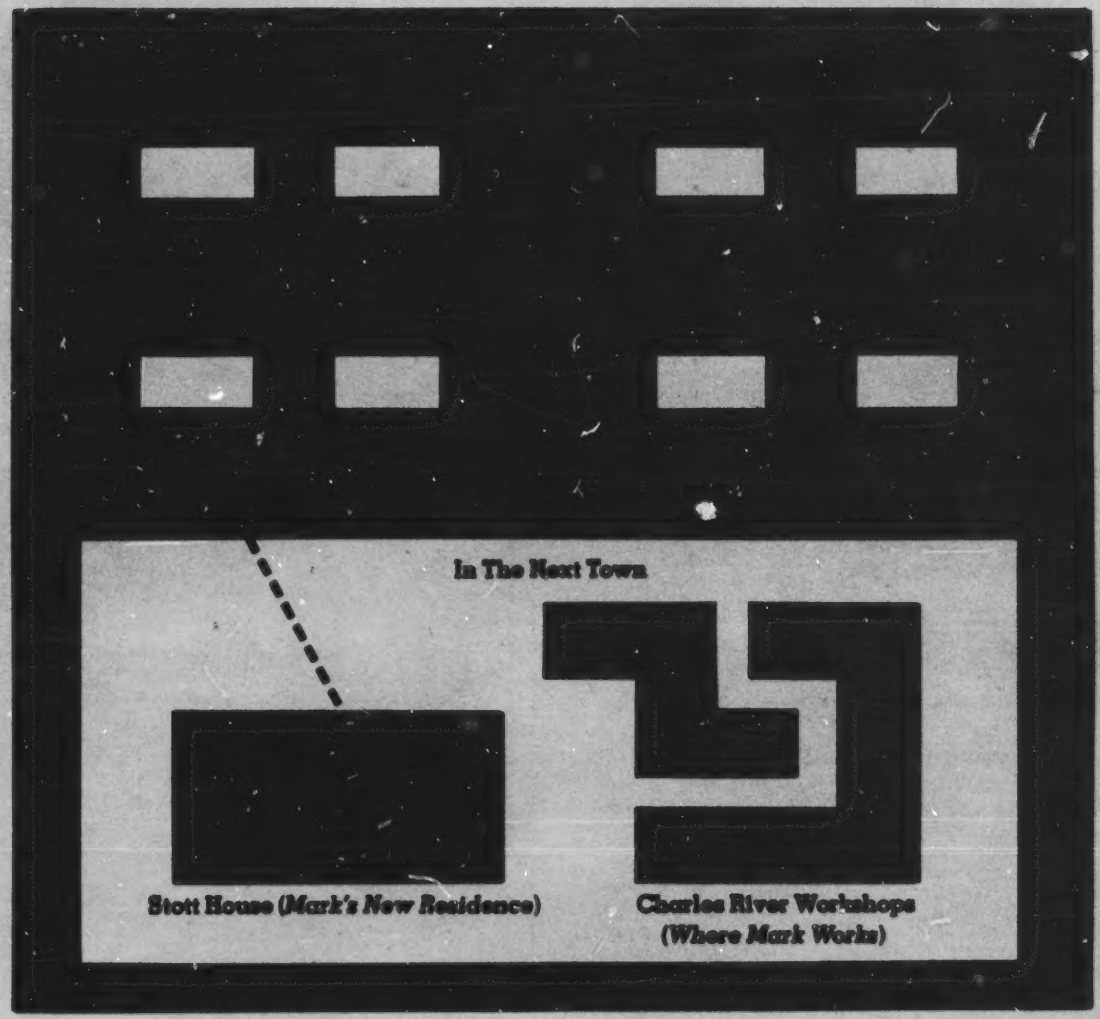
A Mother Explains
by Carolyn Motta

Soon after we moved into our house, the Senatore kids came by. I guess the word got out that this new little boy had things on his legs, steel things. Mark couldn't walk, and the kids would come down and look at him. My stomach would get up in a knot, because I knew they were going to ask questions.

They didn't say anything for the first couple of days, they just looked. Finally, I decided to talk to them somehow, so the next time they came down, somebody said to me, "Why doesn't he walk?" I said, "He has cerebral palsy." I asked if they knew what that meant and they said, "No."

Well, I got out a box of cookies — I mean, that would quiet them while I was talking to them. Then I explained that most people are born with very good brains and could do anything they wanted to do because of being lucky enough to have a good brain. But other people are born with part of their brain damaged. I said, "Your brain tells your legs you want to walk." Then I told them that Mark couldn't walk because the message didn't get through to his feet and his legs.

They accepted it, they never asked another question. They just accepted it and started to play with Mark.



We Tried To Help
by Ann Senatore

One of the biggest barriers parents of children with special needs must overcome is asking for help when they really need it.

After the Mottas moved across the street we realized weekends could be especially difficult for them. Occasionally Mark Sr. worked on Saturdays, so Carolyn would have to struggle to lift Mark in his heavy leg braces.

One Saturday morning, my husband John saw Carolyn wrestling with Mark's wheelchair. Mark was wedged between the chair and a half-opened car door. John stormed across the street, plucked Mark out of Carolyn's small arms, and shouted, "What are you trying to do?"

Carolyn started crying and so did her daughter. John looked at Carolyn and completely ignoring her tears said, "If I ever again see you lift Mark alone, I'll break both your legs." That was John's favorite expression and it always worked. From that time on, John lifted and carried Mark whenever Mark Sr. wasn't able to do it.

Betsy Cole

Ann Senatore

A Trip To The Submarine
by Ann Senatore

One time we saw a story in the newspaper about a submarine and aircraft carrier that were docked at a naval base near our house. So we went to tour them with the Mottas. How were we to know that "civilians are not permitted to inspect the carrier?"

When the officer on duty saw the disappointed expressions of five kids, especially from the one in the wheelchair, crisp, official statements gave way to, "Well, a quick look around the deck would be okay."

After we saw the aircraft carrier, we went over to the submarine which was open to the public. The Navy personnel lifted Mark down the hull, helped push him through the narrow passageways, and hoisted him back up to the deck. Carolyn and I had our hands full with the other four kids, so we were especially grateful for all the help.

When the tour was over, we topped off the day with dinner at a restaurant. This was Mark's first visit to a restaurant, and he loved being the center of attention at the head of the table.

We were all just exhausted when we got home, but Mark was too excited by everything to care about how tired he was.

Mark's Evaluation
by John Senatore

Mark would have to be evaluated periodically by the staff of a local hospital to determine further treatment. The Mottas were naturally nervous and anxious when these evaluations were made. They had been through the routine so many times, and they found it very frustrating when the experts wouldn't believe that Mark understood everything but was very stubborn and uncooperative.

After one session about ten years ago, Carolyn came home exhausted and came right over to tell us about it. The testing, the doctor had said, had been extensive. They had found that Mark's degree of retardation bordered on the level between moron and imbecile.

Carolyn was in a rage. We, too, felt shock, anger, disbelief. Mark, a borderline imbecile? Impossible! Even though he could not read or write, he could understand and talk about everything. Carolyn had asked to see the tests or samples of the kinds of tests that had been used with Mark, but the doctor said he was sorry, this wasn't possible.

Carolyn was bitter. We all just looked at each other, stunned. We knew way back then that the doctor and his tests were wrong.

Betsy Cole

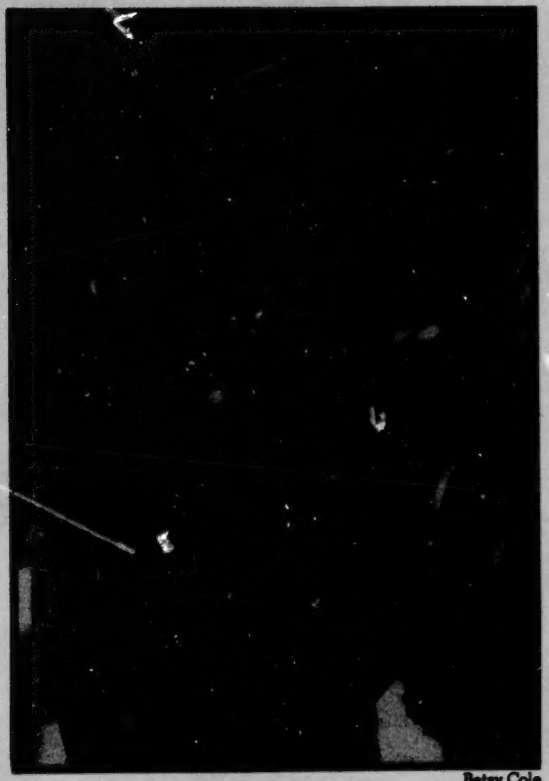
John Senatore, Mark Motta, David Senatore

The Wrestling Match
by David Senatore

My Dad, my brother, and I used to go to wrestling matches every once in a while. So once when Dad said he would take us, I asked if we could bring Mark along. Dad wasn't sure we could manage the wheelchair, but I told him we could so he said okay.

It was really funny when we got there. We took one look at the arena and realized there was no place to set up Mark's chair, so we helped him out of it and got him seated. The only problem was the seats didn't have arm rests, and Mark kept sliding down. So Dad and I sat on either side of him, really close to him and sort of propped him up. That was fine with Mark, he was having such a great time.

The match was terrific and Mark liked it so much that we promised next time we'd take him to see the lady wrestlers!



Debbie Motta

Betsy Cole

Debbie's First Date
by Carolyn Motta

My daughter Debbie was about 13. Mark was in the hospital for a cast, for a jacket. We picked him up that particular day and they told us there'd be no problem. He was in this cast and he couldn't move, and there'd be no problem. Well, we got him home and Mark was in agony: he couldn't breathe, his neck was up like this, he couldn't turn his head, he couldn't swallow. I couldn't even give him water, he'd gag. He said there was pressure on his chest. We didn't know what to do.

In the midst of all this, the telephone rang. It was a little boy from a neighboring town asking to take my daughter out. So I said to Debbie, "No, of course not, you can't date, you're too young. Forget it." "But please Mom," she said. I said, "Look, if he wants to come over here he's welcome, and anybody is welcome in this house, but I will not let you out the door with him, you're only 13 years old." So she said, "Okay, he's coming over after dinner." So needless to say, we had a very hectic few hours with Mark crying and my husband and I debating whether to take him back to emergency and have the cast cut, you know, because the child couldn't breathe. Well, I threw some supper on the table and the front doorbell rang. It was this little boy; he arrived in the midst of all this. He came into the dining area for a while and talked with us, and then they started walking down the hall toward the den where Mark was. Now you've got to picture the scene. Mark is lying on a carpet on the floor. With the cast from his chin and ears down to his thighs. His legs — you know, they're all skinny and deformed, and his feet are flat and his toes point out. He's got his glasses down on the end of his nose; I don't know why he wears glasses, he always looks over them. And they walked down the hall — Debbie and her friend. The boy said, "What happened to him?" Debbie looked at him and said, "Nothing, why?" Nothing! And she kind of looked, you know, quizzical, and then she said, "Oh, well, he just had a cast put on." That was it! I mean, there was no long explanation. That was it. So they went out for a walk and then they came back into the house and Debbie led him right down into the den to watch television. And here's Mark on the floor. The boy couldn't take it. He stayed about 45 minutes. But to his credit, he came back later. He visited us a lot. Debbie still brings her dates in to see Mark if he's home now. Mark's been away for a year, but Debbie's friends are very friendly with Mark; always have been.

Mark's First Paycheck
by Ann Senatore

It was in the fall of 1973, when Mark turned 18, that he started working at the Charles River Workshop. This is a sheltered workshop which provides training and jobs for people with special needs. I remember the day he brought home his first paycheck. He was so proud. He explained that big companies had contracts with the workshop, and I think this made him feel very important.

Each person at the workshop had a special task; Mark's job was to separate large and small screws and put them into different boxes. He said it was just like working on an assembly line. The workers were given a coffee break and a lunch break. He said he and his friends didn't talk very much during working hours because "You have to concentrate on what you're doing, you know?"

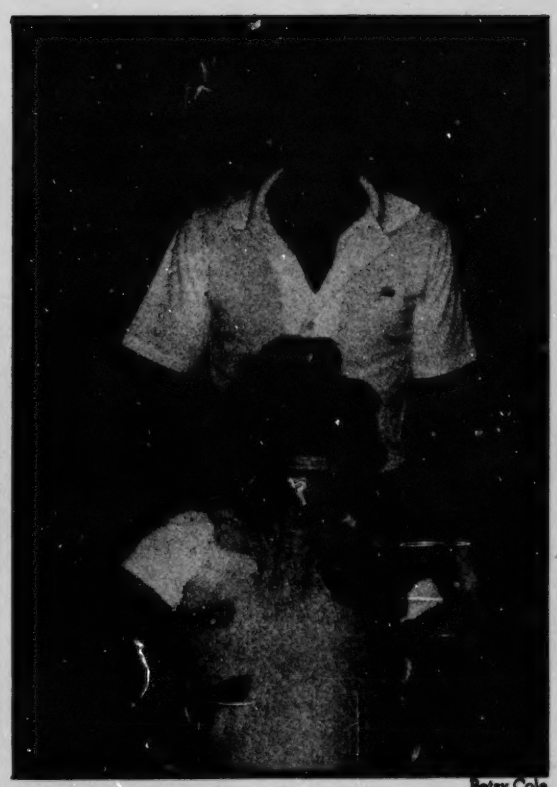
Moving To Stott House
by Ann Senatore

Rumors spread at the workshop that there was to be a second residential home, Stott House, built there. When it was official that Mark would be one of the eight new residents, his parents were overjoyed and sad at the same time. It wasn't exactly like he was going away to college; but the idea of Mark having two homes was confusing for Carolyn and Mark Sr.

However, Mark was looking forward to the move, and he felt reassured in knowing he would not have to stay if he was unhappy in his new home.

It was good that Mark's sister was home from college right after he moved. She was able to help Carolyn and Mark Sr. through their first week of loneliness. We saw many expressions of sadness on Mark Sr.'s face. He missed watching baseball games on TV with his son, and he talked about Mark more during the first few weeks he was gone than any other time we could remember.

Carolyn, on the other hand, mostly kept her feelings to herself. She insisted she was glad he was there. But this had to be the hardest thing in the world for Carolyn. Mark had spent so many years at home with her. But there was no way we could help her.



Betsy Cole

Mark Motta, Stott House Attendant

Mark had mixed feelings. During his first weekend back, he was in a terrible mood and barely talked to anyone. Carolyn tried much too hard to make the visit perfect, and the strain on all of them was very plain. When Mark returned to Stott House Sunday evening, I think it was a relief for all of them.

The next weekend, Mark was undecided about coming home. Carolyn was hurt at his attitude, and told him he had to spend the two days with them.

Mark has a lot of common sense, and I think he realized these weekend visits were not good for him or his family. So he took the first step. On the third weekend, the "house parents" had made plans with four of the residents and Mark joined them.

Gradually the ties loosened, and Mark now spends most of his weekends with his friends at Stott House. Once in a while, I see him zip up in a little sports car, driven by a volunteer, to visit his mother for a few minutes. "I just happened to be in the area," he will say.

Ball games, movies, shopping trips, and outings are all part of Mark's life now. In fact, he has told us to call before coming to visit him. "I have a very active social life, you know, and I just might not be home if you come unexpected."

Betsy Cole

Ann Senatore, John Senatore, Mark Motta, David Senatore, Carolyn Motta, Debbie Motta

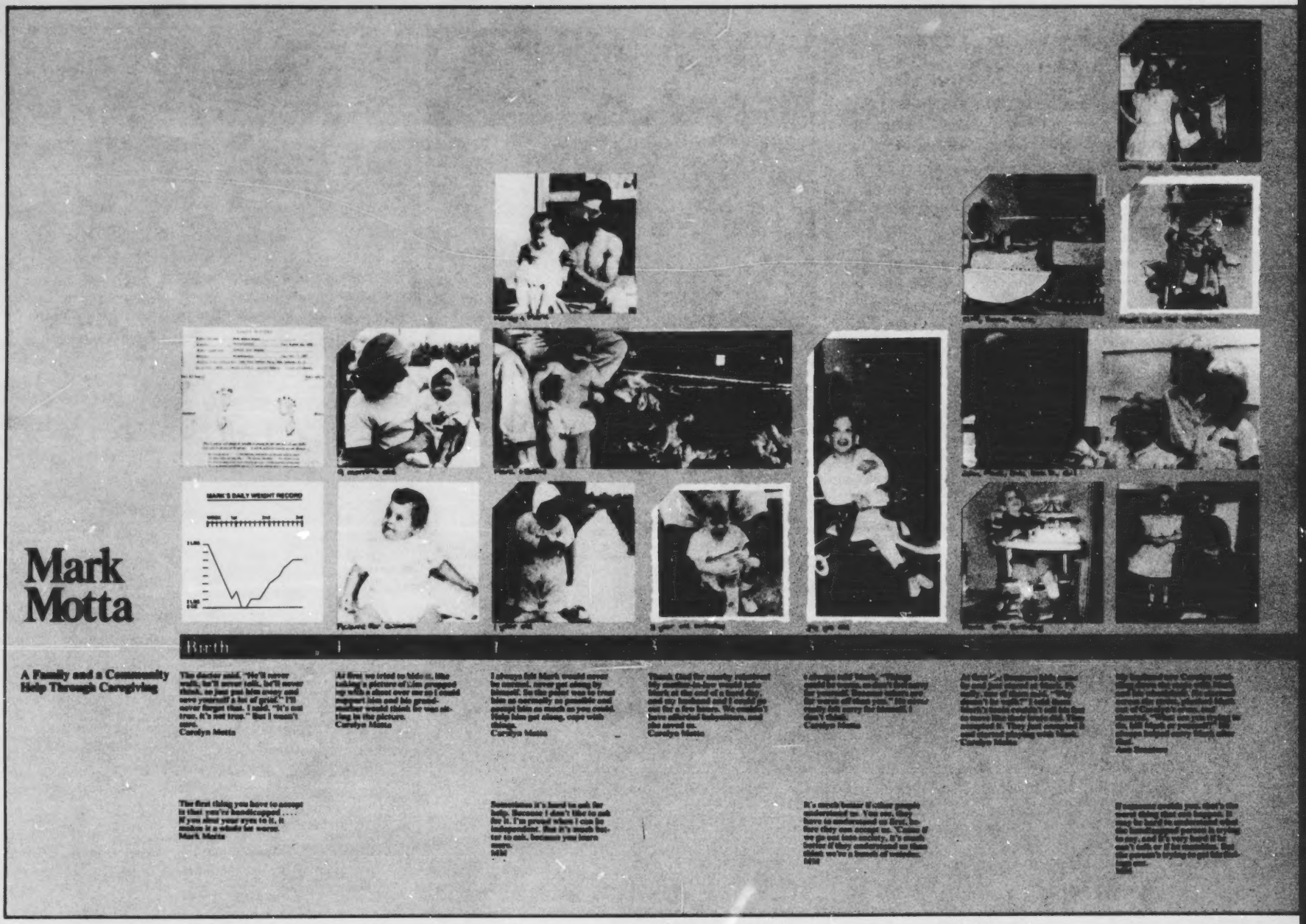
We Still Spend Time Together
by John Roy Senatore

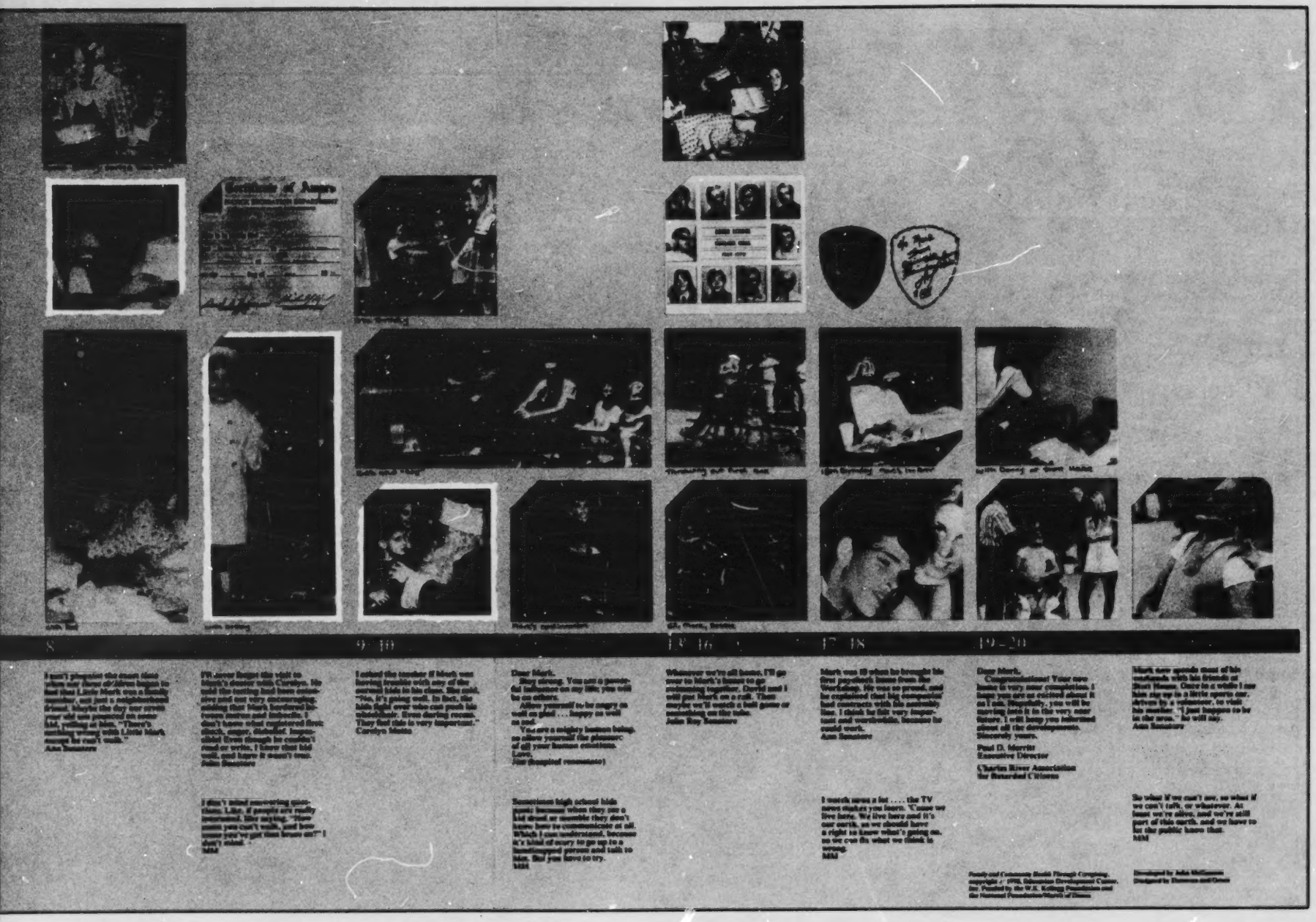
Mark, David, and I used to spend a lot of time out on the front lawn, especially on weekends. We'd just throw a ball around. That was fun. Sometimes Mark would just watch us, and other times he'd play catch from his wheelchair. Even though it was hard for him, he did pretty well.

It's hard for us to spend time together now. I'm away at college, and Mark is out at Stott House. But when we're all at home, I'll go over to Mark's house to go swimming together, and David and I will put Mark on a raft. Then maybe we'll watch a ball game or something on the tube.

Betsy Cole

John Roy Senatore


Mark Motta
A Family and a Community Help Through Caregiving
MARK'S DAILY WEIGHT RECORD
Birth



8 9–10 13–16 17–18 19–20

I don't remember the exact date when your doctor/therapist began to feel that Little Mark was a family member, not just a neighborhood friend. Maybe the day we wrote a letter to you pretending to be your kid, telling us how, "There's something wrong with Little Mark except he can't walk."
Ann Sonntere

I'll never forget the visit to Mark's doctor with Carolyn. He told the visiting med team somewhere and was very encouraging, adding that Mark functioned bi-lingually in sign and [illegible]. I don't know what registered first: shock, anger, disbelief. Impossible! Even though he couldn't read or write, I knew that kid could, and knew it wasn't true.
Ann Sonntere

I don't mind answering questions. Like, if people are really interested, like saying, "How come you can't walk," and how come you've got them braces on?" I don't mind."
Mike

I asked the teacher if Mark was having trouble with any of the normal kids in his class. She said, "No, it's going well. In fact, the kids fight over who can push his wheelchair. Even during recess. They feel this is very important."
Carolyn Mosko

Dear Mark,
Stay strong. You are a person of influence on my life; you will be on others.
Allow yourself to be angry or sad or glad . . . happy or well as sad.
You are a mighty human being, so allow yourself the pleasure of all your human emotions.
Love,
Ann (hospital roommate)

Sometimes high school kids panic because when they see a kid dressed or assemble they don't know how to communicate at all. Which I can understand, because it's kind of scary to go up to a handicapped person and talk to him. But you have to try.
Mike

Whenever we're all home, I'll go over to Mark's house to go swimming together. David and I will get Mark on a raft. Then maybe we'll watch a ball game or something on the tube.
John Ray Sonntere

Mark was ill when he brought his first paycheck home from the Workshop. He was so proud, and he explained that the company had contracts with his assembly line. I think he felt very important and overwhelmed, because he could work.
Ann Sonntere

I watch news a lot . . . . the TV news makes you learn. 'Cause we live here. We live here and it's our earth, so we should have a right to know what's going on, so we can do what we think is wrong.
Mike

Dear Mark,
Congratulations! Your new home is very near completion. I hope you are as excited about it as I am. Hopefully, you will be moving into it in the very near future. I will keep you informed about all the developments.
Sincerely yours,

Paul D. Merritt
Executive Director
Charles River Association for Retarded Citizens

Mark now spends most of his weekends with his friends at Short Stream. Once in a while I see him zip on in a little sports car, driven by a volunteer, to visit his mother. "I just happen to be in the area," he will say.
Ann Sonntere

So what if we can't see, so what if we can't talk, or whatever. At least we're alive, and we're still part of this earth, and we have to let the public know that.
Mike

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Developed by John McGovern
Designed by Sherman and Green

QUESTIONS

Mark Speaks

In the following interview, Mark Motta, 20, talks about being handicapped, his concerns for the handicapped, how he thinks normal people can help, and some of his interests.

Because he cannot read or write, Mark gets most of his information from television news programs. He was eager to tell us his ideas and feelings. He was in a body brace, sitting in his wheelchair, during the interview. He has some difficulty speaking; occasionally he has spasms and garbles words, but for the most part it is not hard to understand him. Toward the end of the conversation, he became tired from sitting.

People have a tough time dealing with the handicapped because they have never been one themselves. I mean, it's hard for the public to understand. Like if you've been normal, then life is a breeze.

When I'm talking about the handicapped I'm talking about the whole thing — mental retardation and physical problems — because I know a lot of handicapped people. I used to be at hospitals with other handicapped people. And most of my friends are handicapped anyway.

I saw that movie with the skier who broke her neck, *The Other Side of the Mountain*. She's a school teacher in Colorado now, and she was practicing for the Olympics and she fell off the hill. And I liked that movie, because she worked like a dog to try and get better. At first, she couldn't face the fact that she couldn't walk. She shut her eyes to the fact that she was handicapped. But she accepted it after a while.

You see, the first thing you have to accept is that you're handicapped. That's the most important thing you have to do. If you accept that something's wrong with you, like mental retardation, or cancer, or whatever the case may be, it's much more easier that way. But you have to accept that first. If you shut your eyes to it, it makes it a whole lot worse.

Pity is the worst thing that anyone can do to us. Like saying, "Oh, I'm sorry for you," or whatever. I mean, I'm sure they mean it, but it's the worst thing they could ever do, to anyone. Because pity makes a handicapped person think they're funny. It just makes them think it's their own fault for what they are.

Sometimes it's hard to ask for help. Because I don't like to ask for it. I'm proud when I can be independent. But it's much better to ask, because you learn more. 'Cause how could you be in the outside world if you had to learn most of the stuff on your own? I realize there's stuff that we all can't do, but you have to improve that stuff you can do.

I'd like to see high school students use their common sense and try to help us out any way they can, because people admire those kids, and they're pretty bright. Sometimes they panic, because when they see a kid drool or mumble they don't know how to communicate at all. Which I can understand, because it's kind of scary to go up to a handicapped person and talk to him. But you have to try. If they can't talk very well, you have to have a lot of patience. Keep asking the person very nicely what they're trying to say. You just can't shut them off. If someone avoids you, that's the worst thing that can happen. I mean, if it takes someone an hour to understand what the handicapped person is trying to say, I mean, the person's trying to get his feelings out, and it's very hard if he can't talk, or if he mumbles or whatever. And the best thing you can do is just to stay there and work with the kid and help him with what he's trying to say. I think in almost all cases the handicapped person wants to talk, but sometimes people don't have the time. They're too busy, going out for rides, or whatever. But if the handicapped had an advocate, which is like a special friend . . . .

If people ask us questions, like if they say, "How come you can't walk?" You know, those are the kinds of questions you don't

Betsy Cole

Mark Motta

mind them asking as long as they don't go too far, and as long as they aren't rude. I don't mind answering questions. Like, if people are really interested, like saying, "How come you can't walk, and how come you've got that brace on?" I don't mind.

What we don't like is prying. Or sometimes they go just a little bit overboard, and it's your duty to tell 'em: "We told you we can't do it, and you do what you do and we can do what we can do."

But kids shouldn't be afraid to ask us things they don't know about. Because that shows interest. That shows that they really care about the handicapped. I'm trying to help all of them out, because I think they have a good role in society to play. And we should use that role to the best of our abilities. So what if we can't see, so what if we can't talk, or whatever. At least we're alive, and we're still a part of this earth, and we have to let the public know that.

It's not that other people don't understand, it's that they don't want to understand. I mean, a lot of times they can go out and look at us like we're funny or something. It's much better if they understand us. You see, they have to understand us first before they can accept us. 'Cause if we go out into society, it's much better if they understand us than think we're a bunch of weirdos.

What I would really like to do someday is go out, and tell other handicapped people to rise and go to the president, and tell him what we want. And I think that someday we should get a march going, and go down there. Demand our rights. Just like in San Francisco, they had a strike. They sat there until he [President Carter] signed a bill for equal rights. They sat there and they vowed they'd never leave. And I wish I were there, too.

The president's doing good in some things, but in others, not so good. Like the handicapped, he's not moving fast enough in my opinion. He's very vague about that. I would like him to make more money available to fix up the state institutions and get new programs started so the kids can get out in society instead of being locked up in bed all the time.

Instead of buying all these weapons for different countries, the president should just try to fix up places for the handicapped as best he can. That's all. You know, make 'em more nicer. So when parents come in to see their kids, it would be much better. It's not only money that's needed, which it is, for new wheelchairs, new hospital equipment like walkers, or whatever. I would like to see programs started where the handicapped could go outside, go around the town, go shopping. Because I think that the handicapped have a role in the society, but the public has to accept us first, before we can go out. And that's a hard thing for the public.

The public has accepted us, but sometimes they give us a little hard time, you know, a little fear they work out of. And they think we're queer. But it's up to us to tell them that we're just as good as they are, and we can do things half or even as well as they can. That's the only way I think the handicapped can go. Because all the handicapped will have a role, if we know what our role is. Because we fought for everything we got. And we have to continue to do that, because if we stop now we won't get anyplace.

Just like, if you want to use public transportation — there's no way we could use that, because it's all stairs. If transportation and public facilities were made easier, that way they could save gas and stuff in the long run. And it would be so much easier on the parents, if you could make public transportation more possible to us, much more easier instead of bringing the wheelchairs and the whole bit. And that would give us a greater feeling of independence. We'd like to do it by ourselves, if we could.

I watch news a lot. I know a lot about the Middle East, and other news . . . the TV news makes you learn. It's extremely important that a person know what's going on. 'Cause we live here. We live here and it's our earth, so we should have a right to know what's going on, so we can fix what we think is wrong. It's not that most handicapped people don't have the right or ability to fix these things, they just don't know how to. You know, like some can't write, some can't see. It's extremely hard for them to let their feelings known.

I don't like to say how long, but I'll be here [at the workshop] for a long time. Maybe in the future I'll leave, but it'll be a long time coming. Who knows? Maybe by that time things will be a lot better than they are now. You just have to wait and see.

It's nice to be living with other young people. It gives us a chance to get, you know, better ideas, and then talk about what their problems are, try to help 'em. Especially if they do it by themselves. There are people with different kinds of handicaps here, and we can help each other. It's much better if the handicapped help each other out. We get to talk together a lot, even at work — usually at break time or lunch time.

I like it here. We work for a big company and we put together television kits. We assemble the pieces. We get our training for that here. I come to work at nine, three o'clock we leave.

After work, we watch TV or talk. I came here by myself, but it's an easy place to make friends. At first it was kind of hard for all of us. It's a big adjustment, but we got it. And in a couple of weeks, everything was okay.

There are eight people living in the house, four men and four women. I don't really know all their ages, but some are young and some are older. I'm not the youngest; Ricky, my roommate is the youngest. He's 17, I think.

We go out to eat, to movies, to baseball games, and swimming sometimes. They take us in the van.

Well, I'm getting tired now. My back hurts a little bit, and so does the brace. And I want to rest, because there's a baseball game on tonight.

Notes From Dr. Cooke: How To Act With People With Special Needs

Dr. Robert Cooke, a pediatrician, is president of the Medical College of Pennsylvania. As a director of the Joseph P. Kennedy Foundation, which helps children and parents with special needs, he has had long experience in working with families of special-needs children. The following passage was taken from an interview with Dr. Cooke.

There often is a lot of discomfort in being with handicapped persons. Perhaps you are not sure how to act in these situations; you know you want to make the person feel comfortable, but you don't know how.

You don't want to feel gawky, so perhaps you start chattering and acting very nervous. Your own stress pushes you to make a big amount of noise and do the wrong thing.

You wouldn't know if a blind man is used to having someone take him by the arm before he goes down a flight of stairs, so you don't know whether you'll offend him by offering to help out. If you're meeting a handicapped person and you're coming into the situation cold, you don't know how much they're used to being helped and how much they can do for themselves. You won't know what they want, and you won't know what they need. What you should try to do, then, is be sensitive to the cues. And if you're still not sure, ask: "Would you like me to take your arm?" "Is there anything I can do to help?" These are the same kinds of things we often do, less self-consciously, with a normal person.

We're constantly looking for cues about which way to go in our social intercourse. We need to listen and observe. The guy who comes blundering in and starts giving a big speech is apt to turn everybody off. His audience just isn't in tune with him at all. Really super politicians are the ones who are the fastest observers. They do a quick sizing up, and they get the cues very quickly and sensitively.

You won't know, at first, whether a handicapped person is used to being handled like everyone else around him and having his handicap ignored, or if there are special needs and expectations. Look for cues to see what you might be doing to help. And don't hesitate to ask how you can help.

Notes From A Teacher's Aide

There are now three major types of educational settings for people with special needs. Some like Steve Slater are mainstreamed into regular public school classrooms. Others like Mark Motta receive training and work in sheltered workshops. And still others are so profoundly retarded that special programs have been set up for them. In the following article, a teacher's aide who works in one of these programs talks about her students and the special qualities she feels are needed in helping them.

For a large group of children, mainstreaming was a giant step forward, but there still were a number of special-needs children who could not participate in regular educational programs. For these children, special programs were developed.

Typically, these students range in age from 10 to 20. Usually they are severely impaired in several areas of development: motor functions, speech and communication, and social and personal habits.

I knew very little about these programs, or the law that brought them into effect, when I joined the staff of the Community Center School as a teacher's aide.

I had no idea the first morning I drove up the hill to the school what a difference the experience of working with students there would make in my life. The building that greeted me was impressive.

As I parked the car, I saw a young girl lying in front of the building gazing up toward the sky. An attractive woman hurried out of the school and told me to just step over the girl. "Janet is testing us to see if we're going to coax her inside. When she realizes no one is going to pay any attention to her behavior, she'll come in by herself." The woman said this matter of factly, without anger.

I inquired innocently if Janet or any of the other students ever became verbally abusive, and the woman looked very surprised. "Janet doesn't talk. None of our kids has speech except for one girl who says a couple of words."

The Community Center School has 17 students and is staffed by a head teacher (something like a team leader), six other teachers or aides, and three part-time therapists: physical, speech, and occupational. Our combined responsibility is to try to prepare these students to become independent enough to leave the school and live in sheltered workshops in community settings.

All of our students have been evaluated at very low I.Q. levels (35 and lower), but we only use this information as a guide to provide special services and help to them. While they are severely handicapped physically and developmentally, each student is a unique human being with distinct personality traits. Just as you wouldn't lump all your friends together simply because they share similar characteristics, we treat each of our students as individuals.

If you are wondering why I refer to these young people as "students," rather than kids or children, it is for the same reason I wouldn't call you a kid or child. Many in our program are in their mid to late teens, and they are entitled to the same respect and consideration that many people are able to take for granted.

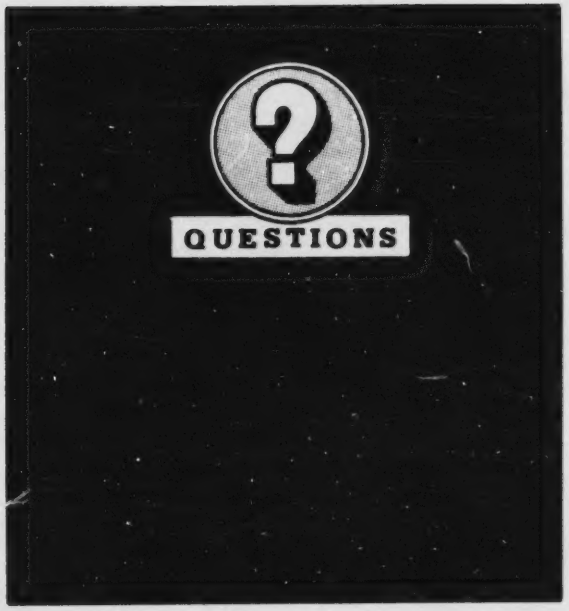
We help our students develop their self-help skills as far as they are able. Toileting, eating, and dressing independently are areas we zero in on all day long. On the part of the teacher, this training requires patience and a calm and consistent attitude. The command, "Go to the bathroom," is not a simple one for our students. It requires the coordination of impulse, reflex, thought, and action. These are very complex steps for our students. It will take a long time for any degree of self-care to be learned.

We break down every task into the smallest skill. By using a steady routine with the students, and by reinforcing every success with encouraging words, we have been able to make progress. We still have a long way to go, and it's impossible to predict when goals for each of the students will be reached.

In the area of motor function (muscular coordination and control, eye-hand coordination, finger dexterity, etc.) our students range from a two-month level to about an 18-month level. Some of them can merely grasp an object but are unable to push or pull anything. Others have the ability to build with blocks.

I worked with a 15-year-old student who could not throw a ball, pull a toy attached by a long string, or push a cart. After six months of daily attempts, he learned to place one large peg in a single pegboard. I felt as if he conquered Mt. Everest that day. I kept hugging him and repeating like a broken record, "Good work, good work." He has since learned to take the pegs out of the board.

The most important qualities for working with these students are patience, a sense of humor, and common sense. Concern, caring, and a real interest in helping them toward the goal of living in a community setting also are essential.



CASE STUDY

Ellen's Story
"They've really helped a lot."

Ellen was 15 when her daughter Cherice was born prematurely. Cherice was born with cerebral palsy, a disability resulting from damage to the brain before or during birth. Ellen's youth may have been the reason why her daughter was born with a problem, or it may not; the causes of cerebral palsy are not fully understood. As you listen to Ellen's story, consider:

- *How did Ellen's youth affect the way she handled her pregnancy?*
- *What supports did Ellen receive, during her pregnancy and after Cherice's birth?*
- *What special qualities and coping skills has Ellen shown as the mother of a handicapped child?*

Cherice is four years old. She has cerebral palsy in her legs. When she was born she couldn't walk. When she was two years old, that was when she first started walking, two and a half. Before that she couldn't.

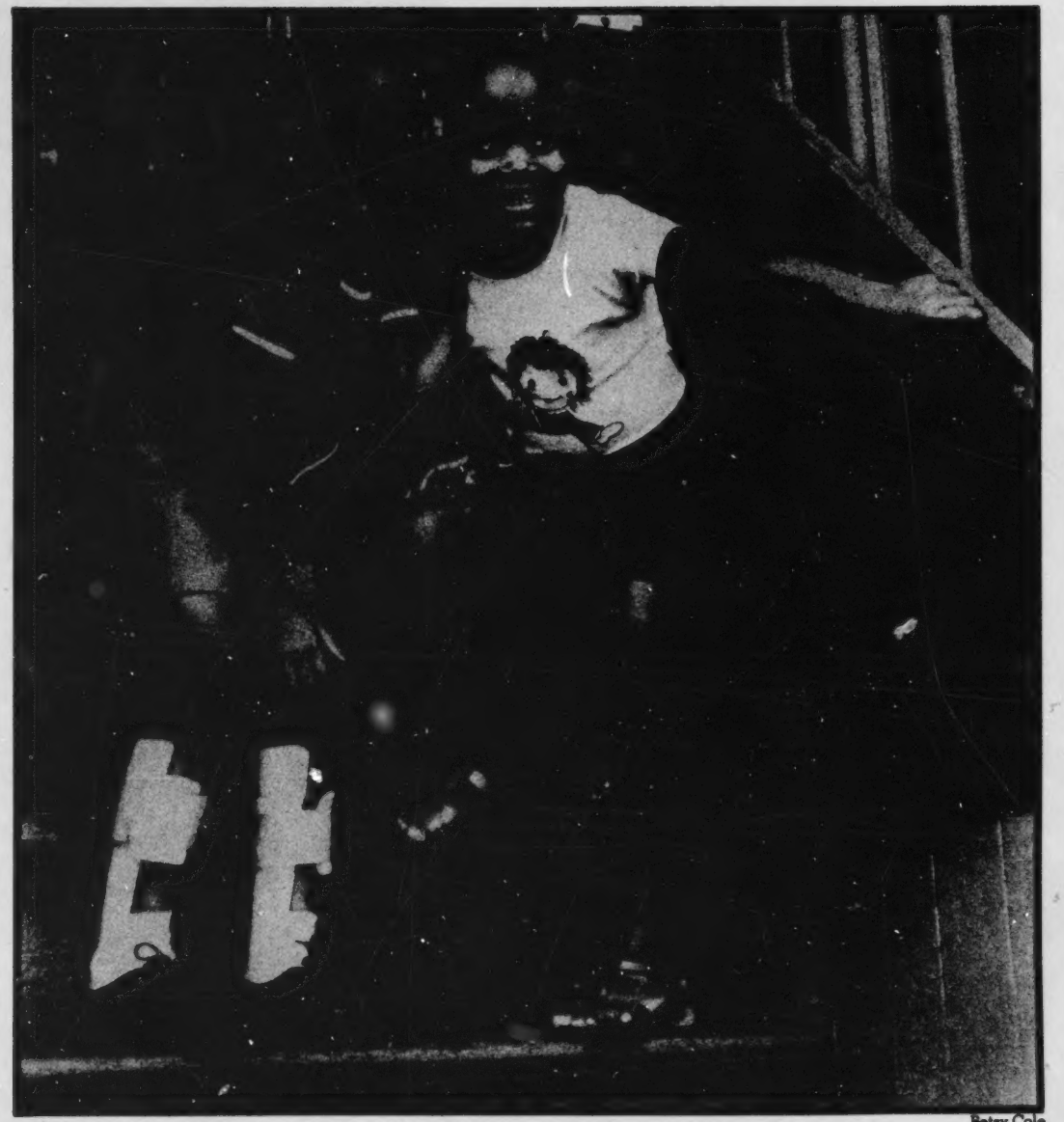
I know it's a birth defect, and I figure the reason why Cherice has had it is because I was only 15 when I had her. I only went seven months. And I know full-term babies are the most healthy babies, whereas anything under nine months, especially seven — it was barely seven, six and a half to seven months. I was lucky that she lived.

Well, I was pregnant at 14 and had her at 15, you know. I was going through a lot of changes about what my parents thought of me and what I was going to do. I wasn't too sure if I was going to stay home or whatever, but I knew I was just too young to try to make it on my own out there with the baby. So I thought my best bet was to be at home with my family. They really helped a lot. But I guess I knew what I was in for.

I waited until I was four months to tell my mother that I was pregnant, you see. So there was four months of prenatal care that I had missed. Maybe if I told my mother that I was pregnant when I first knew. 'Cause I couldn't get examined by the doctor 'cause I was under age. I was only 14. I had to tell my mother, and I told her when I was four months pregnant, and three months after that I had the baby. So I really missed a lot of prenatal care.

Well, from the beginning I knew there was something wrong with her, because she was a 2-pound 13-ounce baby. And I know

Betsy Cole



Betsy Cole

when premature babies are born, they are the ones who are most susceptible to birth defects. The only thing you can do is wait and watch.

My sister had a baby about the same time I did. My sister's baby was born in November, my baby was born in August, so what I did was compare them. When my sister had her baby, she was a grown woman. She was 22. I was still a child. Her baby went the full nine months, my baby didn't. My baby only went seven months. So I sorta like compared them two. And when Valerie was sitting up at about four or five months, Cherice wasn't. Cherice was still laying down. Cherice had a hard time pulling herself out of the crib, which Valerie didn't. Cherice would cry a lot. She wouldn't cry, she would scream when she was a little baby. Valerie would sleep all through the night, whereas Cherice wouldn't. Cherice would wake up something like every three hours and she wasn't hungry, it's just that constant crying. I would have to wake up in the middle of the night, and go back to sleep, and try to go to school, and so that was really kind of hard.

And like we live in a one-family house, and the bedrooms are on the third floor, and the kitchen is on the first floor. And I have to run down three flights of stairs to get the bottles or whatever, so . . . .

And that's what really caught my eye to things. What I thought I needed to do was take her to certain specialists and find out what I could do, to improve her present situation. So I was at the clinic, and they don't have a pediatric department. So I was at the Health Center and they didn't really specialize in handicapped children, so I transferred her to Children's Hospital Medical Center. And when I did that, that's when I felt a whole lot better. Because there were lots of specialists there — neurologists, and orthopedics, and physical therapists — which I think gave me a lot of moral support. So I guess that really helped me a lot.

I stay home with my parents and my family. And that helped a lot, too, because there is a very large family at my house. See, I have my mother, my father, and there's five of us. Everybody takes turns.

Two of my closest friends were really a lot of help to me. They would baby-sit for me. When Cherice's birthday came, they would help me give a party and things like that.

Her condition gets better as time goes by. As long as she keeps having the regular therapy, as long as her muscles in her ankles and in her hips don't tighten back up on her, that's her problem — her muscles were too tight. So what they did was give her an operation to lengthen her muscles. She sleeps in a night brace to keep her legs in a certain position, and if she's not in that position her muscles would just slowly but surely tighten up back on her. And if so, then she won't be able to walk. Without the braces and the shoes, you would be able to tell her handicap right off. If she had a regular pair of shoes on she'd walk tipsy-turvy, but the braces help her keep her balance.

At one time the doctor told me maybe when she's about 12 or 13, they may come off. As time goes on her condition improves from what she did when she was a baby, and when she was two years old, and what she is doing now. We—you know, you just have to wait and watch and see and keep your fingers crossed.

Cherice knows that what she's going to the hospital for is going to help her better herself. So it's not really that she dreads going; she loves to go to the hospital, because they make it seem so playful.

Right after she had her operation, she snapped into a lot of things really fast. That's part of her therapy, riding her tricycle, taking a walk up a hill. She takes swimming lessons once a week. She's been doing that for two years, and she's really swimming good. This past summer she went to Day Camp and she really liked it. She had a good time there and I think they helped her a lot. But even though that's a school for just able-bodied children, they took in Cherice and she fit right into the classroom situation. She just really loved it and they loved her. From that right there, I know that she can fit herself into a normal classroom-type setting without any problems.

Betsy Cole

Betsy Cole

And I hope to see Cherice go on to a good school. I mean a really good school. She'll be five in August. She's old enough to start kindergarten. They want to send her to the same elementary school that I went to when I was Cherice's age and the school is about 100 years old. The girls' bathroom is way down in the basement and the classrooms are upstairs, and I just can't see Cherice going up and down four and five flights of stairs, even though she can, but I won't want her to do that. I would much rather see the bathroom on the same floor. And transportation too. That's another thing I have to look into for her, make sure they pick her up and make sure they bring her home.

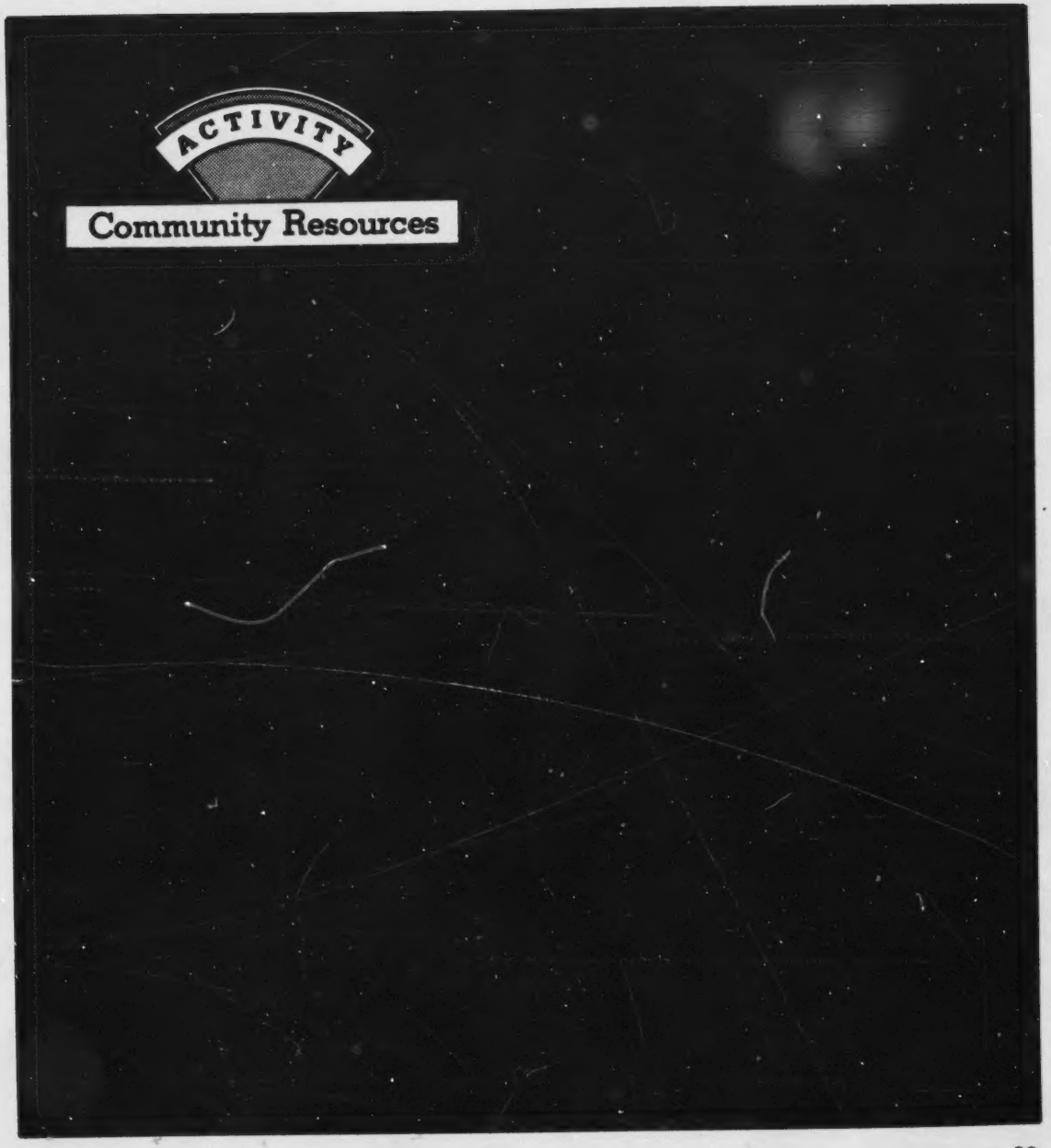
I would like her to be close, so in case something did happen to her in school I could be notified really fast, and get there. The most important thing I think she needs is therapy. And where she goes to school I think that she should have some kind of physical therapist there, doing her exercises with her. Because I can't do them with her, because I'm not with her during the day. And with those kind of people around I would feel a little bit more better. I could go to school without worrying about Cherice. So I know I'm going to have a really hard time finding a school I want.

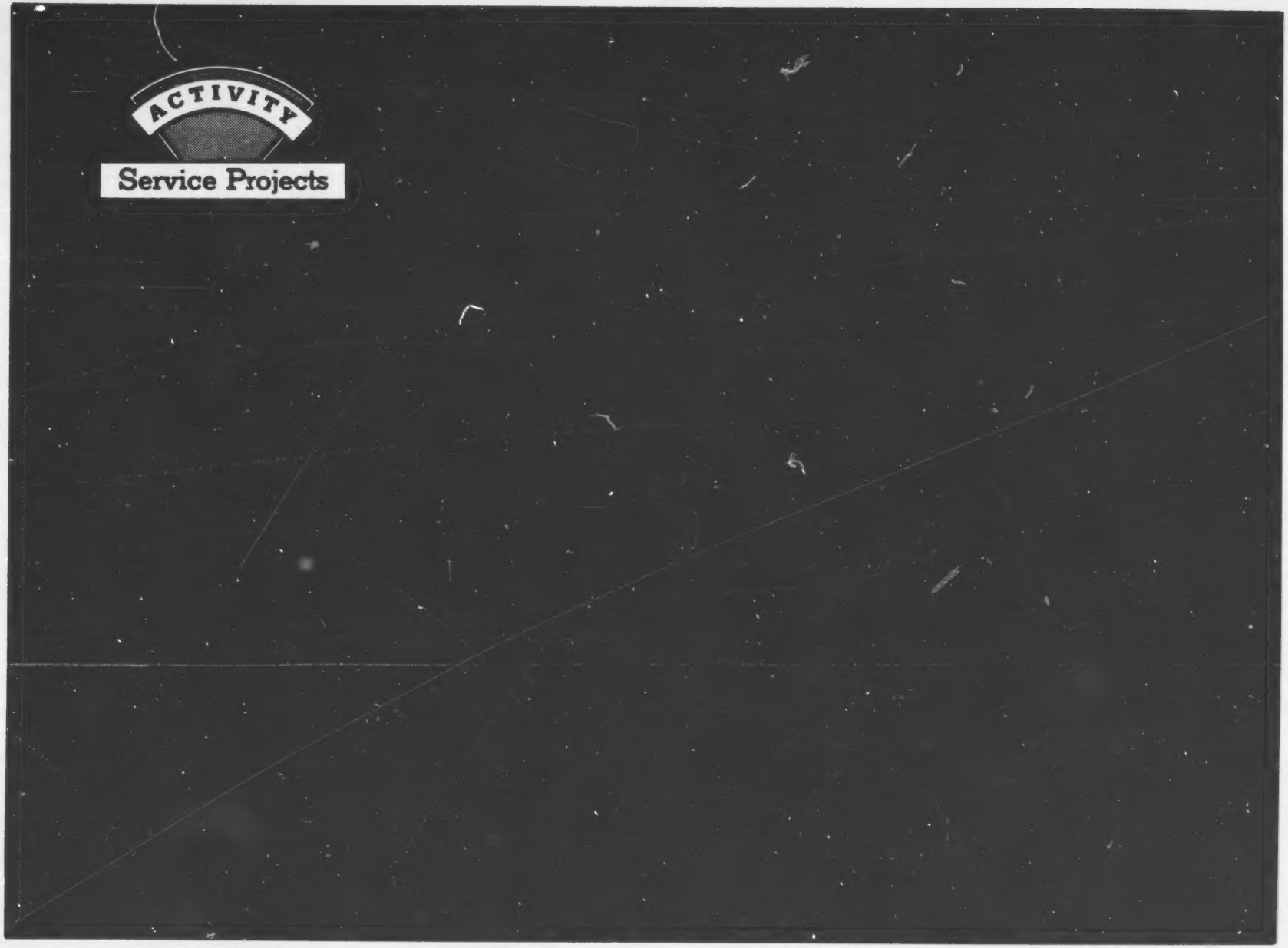
Well, there's a lot of other things that I want, and I just have to fight for them. Like I fought for what she has today now. Because it's really hard, trying to get certain things for her, like her braces and eye-

glasses and corrective shoes, and schools, and therapists, and things like that. I have to let them know six months ahead of time when it's time for her braces so I won't have to wait and so they won't pinch her legs to death in the meantime, because she is growing and you know kids grow and they grow out of things.

But it is a big financial strain. Because like her braces, they cost $90.00 each, a leg. Then there's shoes on top of that, then there are eyeglasses.

I also shopped around for a lot of doctors. I went to all different clinics until I was really satisfied. You know, you have to watch them at least a year if you think that there is something wrong with your baby, and you're not satisfied. And I think when young girls do have their babies and they're not too sure if they do have birth defects, that they should take them to a hospital that does specialize in children. They've really helped a lot.




ACTIVITY
Service Projects

Helping Ourselves: How Parents Affect The Health Of Their Children

So far, you have considered many of the ways you might help others and encourage healthy families. What about yourself? Most of you will become parents at some time in the future. If you think you will ever have a baby, you have a responsibility to your future child to know now what makes babies healthy.

A baby's health starts with its parents' health and family genetic history, long before it is conceived: what you eat now, what you smoke or drink, the drugs you take, the health care you get, hereditary defects in your family, the physical environment you live in now — all of these can affect the future health of your children. Caring for yourself now and knowing your family history can make a difference to your children later.

It's important to know how babies get a healthy start in life for another reason. Babies develop significantly as soon as they are conceived. So much happens to a fetus in the first seven days, before a woman can know she is pregnant, that you should know what an expectant mother needs and where to go for information if you think it's even possible that you and your partner have conceived a baby.

Some of what you read in the following material will apply to your life right now; some will be important later, when you're planning to have a baby or think you might be pregnant. Even if you don't remember everything you read now, when the time comes to prepare for having a baby, you may remember the categories of things that matter and where to get information.

In this section, you will read about things you can do that may make a difference. One important thing to remember is that males as well as females play important roles. While a mother must make decisions that directly affect the baby's health (for example to stop smoking), the father can play an important supporting role by providing encouragement (for example, encouraging the mother not to smoke by giving up smoking himself, or not smoking when he is with her).

Before you read about the factors that influence the development of healthy families, make a list of the ways you can help from the material you have already read and discussed.

Ways I Can Help During Pregnancy	
If I am the father	If I am the mother
Encourage the mother not to smoke by giving up smoking myself.	*Stop smoking.*

Try to think of three distinct categories of helping: physical, emotional, and social/environmental. Add to this list for fathers and mothers as you read the next section.

Your teacher may ask you to read this section at home while you are working on other materials in class; or your class may divide into small groups, each group studying one factor that affects the health of children and reporting to the class.

John McGannon

A New Kind Of Checkup

Sherry Thinks About Her Checkup

My mother has suggested to me that I start going to a gynecologist. I'm really scared and embarrassed. I don't have any idea what goes on in an examination, and I think my mom is being premature about the whole thing. But she said that that was the kind of doctor I would be seeing for the rest of my life, and that it was a good idea for me to start going to one now, so when I really needed one, like when I got married, I would already have one who knew me.

One of the girls in my gym class started to see a gynecologist last year, and one day she told us all about it. She said that the doctor stared at her all the time, and that it was very painful and embarrassing. She also said that she had had to go in all alone, and that the doctor had asked her all kinds of weird things about her period and stuff, things that were none of his business. And she showed us how big the clamp was that he put inside her.

I don't know how much of what she said to believe, but there are lots of things that I'd like to know about. Like, will it hurt? Will the doctor ask me about personal matters? How long will it take? Will my mother come in with me? Will there be a nurse?

Another thing that bothers me is that I just can't imagine what it will be like undressing in front of a man. I haven't had a man see me in my underwear since I was a little girl, when my dad used to give me my bath. I don't think that I could ever go in front of man without any clothes on. Another thing that makes me nervous is what my friend said about the doctor looking at her funny. I'm not looking forward to that appointment at all.

To Think About

Do you think that the information Sherry got from her friend in gym class is accurate, or do you think that she exaggerated?

Can you think of other questions you would like answered?

A Mother Talks To Young Women

I think it's a good idea for a young woman to have a routine internal checkup after she begins to menstruate. It's reassuring to find out from an expert that you are in good shape and that everything is developing normally. And it's a good time to have your questions answered in a professional manner. Once you get to know a doctor, you will find it is easy to ask for advice, because you are already a familiar face, and the doctor will have a special interest in helping you.

Sometimes a girl will worry unnecessarily about this kind of doctor's appointment, because she doesn't know what will happen or because she is afraid it will be an embarrassing experience. I can remember feeling that way when I was your age; now I have a special reason for talking to young women about this, because I have a daughter of my own, and I would like all of you to know what to expect.

You may feel comfortable going to your family doctor; or your family doctor may recommend a specialist. There are free clinics if you cannot afford to go to a doctor in private practice. The best way to get information about clinics is to call your local Hot Line or your community health center.

It's hard to think of the more private parts of your body in the same way that you would think of your ears or your little finger or your big toe. But remember that a doctor, especially a gynecologist (a doctor who specializes in the female reproductive system) or an obstetrician (a doctor who specializes in pregnancy and birth) is a professional with special training and knowledge about a woman's reproductive system. Your examination is a very routine procedure. And he or she *does* think about a vagina in the same way that an ear, nose, and throat doctor thinks about an ear canal.

Doctors and nurses try to be sensitive to a person's feelings of privacy and modesty. For instance, you may be asked to keep your slip on, or perhaps you will be given a paper gown to wear. And the doctor will use a sheet while he is examining you.

The doctor will want to know some routine things about you: he may weigh you and check your teeth, heart, lungs, and breasts before starting the internal exam.

The examination is not painful, especially if you are comfortable and relaxed. When you are tense, anything can feel less comfortable. If you are concerned about the instruments that the doctor will use, you can ask to see them and have their use explained.

Never be afraid to ask questions. When you talk to your doctor you will not be expected to know long, scientific words, so use phrases you are familiar with; you will be understood even if you use slang.

And the doctor will be pleased to explain what is happening to someone who is sensible enough to want to know the answers.

Doctors are becoming more sensitive to women's feelings, and will do all they can to make the examination as comfortable for their patients as possible. Sometimes a very simple change in procedure can make a big difference. For instance, the instruments may be warmed to body temperature before they are used, so the metal doesn't feel cold on the skin.

It's helpful to know that what you tell your doctor, and what your doctor tells you, is private, just between the two of you. A doctor will not give anyone information about a patient. That is a professional promise. And it is true whether the doctor is in private practice or with a free clinic.

After you have seen the doctor, you will be pleased that you have acted in a responsible way in caring for yourself.

To Think About

Do you think this is something you should talk about with your parents?

If you are a boy, do you have a sister with whom you could share this information?

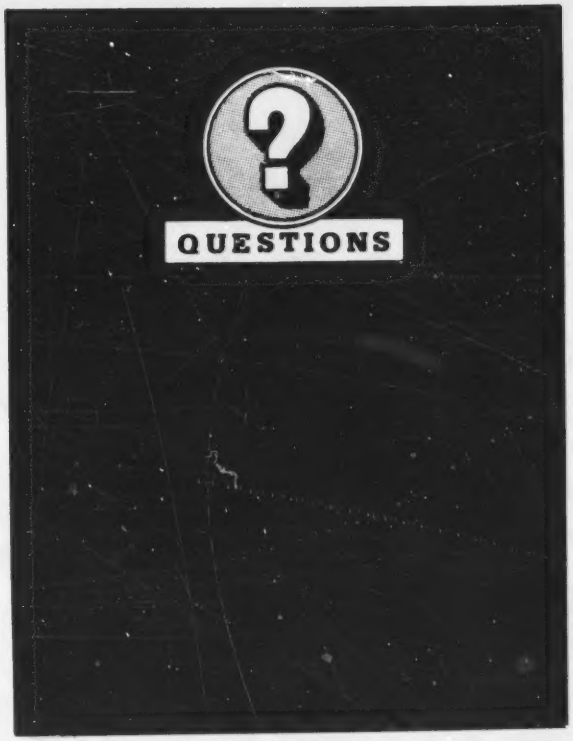
Fostering Healthy Growth

A baby's future health and well-being can be encouraged or harmed by factors in the environment during pregnancy and after birth. Some important factors that may influence a baby's health are:

- prenatal care
- maternal infections
- nutrition
- medication, alcohol, tobacco, and other drugs
- environmental hazards
- family income
- parents' ages

No one factor operates alone; each influences the others. As you read about each factor, think how it may be influenced by some of the others. Think about possible links between:

- nutrition and family income
- family income and prenatal care
- parents' age and prenatal care
- parents' age and nutrition
- family income and environmental hazards
- prenatal care and maternal infection
- prenatal care and environmental hazards
- drugs, alcohol, and prenatal care



To Think About

- Most people try to get the best available medical advice when they find out they are going to be parents.
- Parents must rely on advice from experts when the mother or the baby has a problem too complicated for the parents to solve themselves.
- Advice can go out of style from one generation to the next.
- Advice can change with new medical research. For example, recommended weight gain during pregnancy has increased in the last ten years.
- Advice can change when the conditions change.
- Some advice can turn out to be harmful after serious damage has been done.
- No parent knowingly takes advice that turns out to be harmful.
- Parents should not be blamed or made to feel guilty when something they did with good intentions turns out to have unfortunate results.

Health Resources Yellow Pages

Throughout this section, you are asked to identify people, programs, and agencies that work for the health of children and other people in your community. As you do this, individually or in groups, add your findings to the card file, or "Yellow Pages," that your class began while doing service projects in the first section of this book. This file can be a resource for everyone in the class, and possibly even for others in your school and community.

- Include the name and address of each person or agency contacted and the date of contact. Add your own name in case others want to ask further questions.
- Outline or summarize what you learned from each contact.
- Organize your entries so that others can use your file (perhaps by topic or alphabetically).
- Include newspaper or magazine clippings that relate to the topic or entry.

Date:
Agency Name:
Address:
Phone:
Person Contacted:
Summary:
(Add your own name in case others want to ask questions)

John McGannon

A Baby's Health Is Influenced By:

Medical care for the mother while pregnant and at the time of birth.

Prenatal care is extremely important to have early and regularly during pregnancy. In Sweden and some other countries, nearly all pregnant women receive early and good prenatal care, care at the time of birth, and care for the infants immediately after delivery. In these countries, the number of miscarriages and premature births, as well as the percentage of children born with defects, are much lower than in countries with little or no prenatal care.

In New York City, pregnancies involving medical, social, and economic risks were studied in terms of the prenatal care the mothers received. The babies of women who received early and regular care weighed more at birth; fewer of their infants died. This was true for women with previous pregnancy complications, for women who were teenagers, unmarried, or poor, and for women who had both medical and social risks.

Pregnant women should receive medical care throughout pregnancy. This is not because they are sick: pregnancy is not a disease. They need it because their unborn babies need the best possible start in life. The mothers need a good diet and proper exercise; they need to take special care to stay healthy. Regular checkups with a doctor, who watches for early signs of anything that might go wrong, allow complications to be treated early.

A Baby's Health Can Be Influenced By:

Infections of the mother during pregnancy. Maternal diseases that are dangerous to unborn babies include rubella (German measles), some other viruses, and sexually transmitted diseases (STD*).

Women with untreated STD often suffer complications in pregnancy. Their STD can harm the baby before or during birth. Rubella in women early in pregnancy can cause deafness, heart disorders, mental retardation, and other defects in babies. Some women who get rubella in the first three months of pregnancy have miscarriages. The last outbreak of rubella in the United States in 1964-65 caused about 30,000 children to be born with defects. Each year more children are born with birth defects caused by rubella.

When couples apply for marriage licenses, they are always given a blood test for syphilis. Now some states require a second test in women for rubella. All teenagers should be tested for both.

Three common forms of STD in the United States today are syphilis, gonorrhea, and herpes simplex II. Syphilis and gonorrhea can be treated with penicillin, and both can be tested easily, the former by means of a blood test and the latter by examination of a culture from the cervix, penis, throat or anus. Public health officials think there are about a million untreated cases of these diseases in the United States at any one time. About one-fourth of those who get syphilis and are not treated die from it eventually, or are blinded, crippled, or mentally impaired. The effects of untreated gonorrhea are not as severe, but the womb, heart, and other organs can be harmed seriously.

The symptoms for syphilis in the first stage (9 to 90 days after contact) are sores or blisters that are usually not painful and are located mostly on the genitals, but also on lips, tongue, anus, breast and even fingers — wherever contact is made. (However, the sores may not show up, especially in women.) Later (from six weeks to six months or longer), there is a rash on the whole body or the limbs, aching joints and bones, and flu symptoms like a sore throat, headaches, and nausea. Loss of hair can occur. After this period, all the symptoms disappear; but the disease continues, without the person's knowldege, for 10 to 20 years before the final symptoms show up.

It is possible, especially if you are a woman, not to know that you have syphilis; it is even more likely that women may not know if they have gonorrhea. Men, and some women, have pain while urinating, and a pus or discharge of the penis or vagina. A nagging sore throat or irritation of the anus can also be symptoms of gonorrhea if sexual contact has been made in those areas.

Herpes simplex symptoms are painful cold sores in the mouth or near or on the sex organs, sometimes accompanied by swelling. A mild sore throat and mild nausea may also occur. These symptoms may last for 10 to 14 days. It is not uncommon for the symptoms to recur from time to time. Herpes simplex II kills more newborn babies than congenital syphilis. Presently there is no cure for it.

All STD is contagious, and can be passed on through contact with the sex organs, mouth, anus, open sores. Syphilis also can be received through contact with sperm or discharge from sores that contacts the eyes, nose, or even sensitive skin.

For these reasons, if you are sexually active, get blood tests and cultures for all possible forms of STD at all points of contact. If you have any symptoms of STD, see a doctor immediately. It is especially important for women to be checked regularly, and for all persons who find out they have STD to let their sex partners know at once. It can be a matter of life and death.

Treatment for syphilis and gonorrhea is painless and now widely available. In most places it is free and confidential, for teenagers as well as others. Lately, in the United States, STD has almost become an epidemic. Rich people, poor people, old people, young people, educated and uneducated, city and rural people have all had it. For many people,

*Sexually transmitted diseases (STD) — traditionally called venereal diseases or VD.

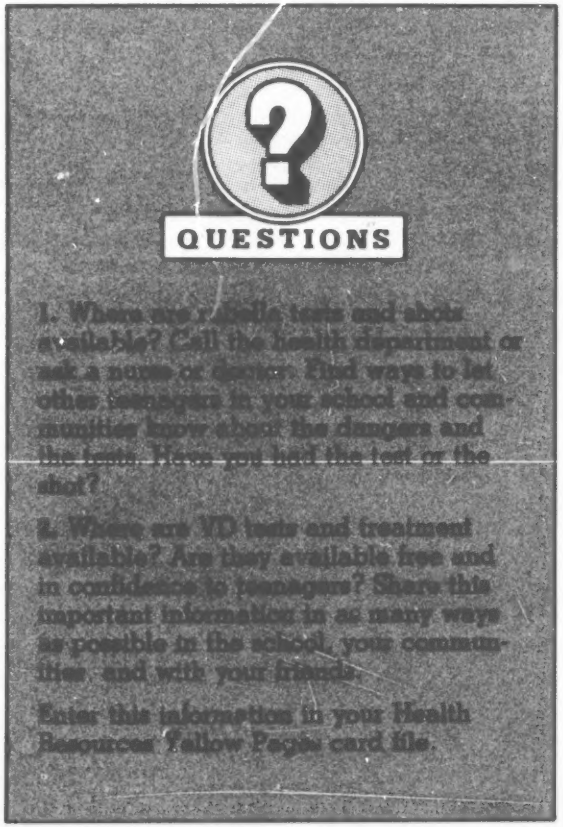
Susan Wing

it is not as strong a cause for shame or embarrassment as it once was, which makes it easier to seek help. But if you think you might have a sexually transmitted disease, and feel unable to admit this to anyone — even a doctor who will treat the information as confidential — it is crucial to overcome these feelings and have a checkup. Otherwise you are risking your own life, the life of any sex partner you might have now or in the future, and the life of any children you might have.

Women can take a blood test for rubella to see if they have had it already. If not, they can get a rubella shot when they are sure they are not pregnant. Women who might be pregnant should not get the shot since it can damage the fetus. Women who take the vaccine should wait four months before becoming pregnant. Since 10 percent of the shots do not "take," they should have another test eight weeks later to make sure. The symptoms of rubella are a fever or rash, but they are often so slight that women don't know when they have it. All women should have the blood test.

Women who are pregnant and find out they have syphilis can still be treated for it at any time during pregnancy. If the mother is treated before the middle of pregnancy, the chances are the baby as well as the mother will be completely cured. Gonorrhea can be treated at any time during pregnancy and usually mother and baby will have no serious

problems after treatment. Syphilis and gonorrhea are treated simply by doses of penicillin. Since the test is not 100 percent accurate, it is best to have two tests about two weeks apart if you think you have been exposed to STD. Also, if you do have STD and have received penicillin, have the test again after a few weeks to make sure it has been cured. If you are being treated, it is safer not to drink alcohol. Penicillin can cure both syphilis and gonorrhea during the first three stages, up to 20 years after contact.



A Baby's Health Is Influenced By:

How well nourished the parents are.

When a pregnant woman is not well nourished, her baby is affected. Babies born to women with severe diet problems almost always weigh less at birth than babies born to well-nourished women. Studies of babies born in Holland during World War II during famine show that the average birth weight was half a pound less than in other years. In Russia, during the siege of Leningrad, babies weighed a pound less, on the average, than babies born in normal times.

Malnutrition is tied to poverty. Babies born to poor families in Guatemala, Chile, Brazil, and other developing countries are almost one pound lighter than babies from rich families in those countries. In the United States, the difference is about half a pound. Poor eating habits and fad diets, both of which are sometimes found among teenagers, can result in malnutrition, even among people who are not poor.

Malnutrition throughout the mother's life or throughout the baby's childhood is far more serious than *acute* malnutrition during pregnancy. We know that situations like those in Holland and Russia during World War II can be reversed if the children are fed well after birth. The effects of long-term malnutrition are greater and more lasting.

Strong evidence now exists that children born to poorly nourished parents are more likely to be mentally retarded, or at least lower in intelligence, than other children. Human brain cells are not produced continuously throughout life. The most active period of brain cell growth is in the last three months of pregnancy and the first three months after birth. Animal studies show that the total number of brain cells is reduced when the infants or pregnant mothers are fed poorly. The same thing probably happens in humans.

Probably the development of a baby's brain is harmed if the mother is malnourished. When such a child is born into a family that is malnourished, things get worse. The baby's fast-growing brain can be injured further by a poor diet in infancy. The baby is more likely to catch infections than a well-fed child. This makes the situation still worse, since a sick child usually doesn't eat well.

ACUTE: sudden and serious.

Susan Wing

Direct injury to brain development is not the whole story, however. The growth of intelligence is a complicated process. It depends on the child living with, exploring, and responding to many things and people. Young children need stimulation from the people around them — people who talk to them, cuddle them, play with them, and teach them about the world they live in. When the people who take care of the baby are not fed well, they may lack the energy to engage with a baby. Babies who are sick or irritable because they are poorly fed do not bring out the best in parents. If parent-infant contact is low, and if parental response to the infant's signals (crying, laughing, reaching, etc.) is lacking or very slow, mental growth is apt to be affected.

The connection between malnutrition and mental retardation means that many children in the United States and other countries may be seriously handicapped simply because they are not getting enough of the right foods. But the situation is not hopeless. It can be improved if we see that all children receive enough nutritious food during their first two years.

Diets For All Teenagers

What we have said so far has to do with severe malnutrition. What about the effects of diets that are not good, but not close to starvation? Less is known about this, but it is clear that even mild nutrition problems can damage the mental and physical growth of babies. Frankly, the field of medicine has not known as much as it should about nutrition in the past. Recently, more attention has been given to the role of diet in good health. There is a better understanding of the damaging effects of various chemicals in processed foods and of the need for vitamins. Health foods have become more popular, and quite a few people are becoming vegetarians or eating less meat. We do know that Americans eat too much fat, salt, and sugar, and that these eating habits cause all kinds of problems for children and adults. We also know that more and more foods contain chemicals to help preserve them, to give a better taste, to enhance color, and for other reasons.

Several studies have shown serious health problems among children and teenagers who eat regularly at fast-food restaurants where the food is greasy, filled with additives, and has little nutritional value. Junk food "junkies" are everywhere these days, and most people know both the craving for this kind of food and the way they feel when they've eaten too much of it.

Some women who are pregnant have heard about toxemia, once mistakenly thought to be associated with overeating. Hence they may be afraid to eat too much. Toxemia, however, is usually caused by undernourishment. The real danger to women is that they will eat too little, or get too little of the right foods. Pregnancy is not the time to diet, and it is the time to heed a doctor's advice about vitamins and food.

Food For Mothers-To-Be

When you look at your diet as a potential parent, there are several things to remember:

- Don't make sudden changes in diet, and don't take vitamins without a doctor's advice.
- Avoid eating too much of anything, especially processed foods, junk foods, and food from fast-food restaurants.
- The more fresh, natural foods you eat the better.
- Good nutrition is built up over a lifetime. Poor eating habits cannot be made up for entirely during pregnancy.
- Adolescence is a time of rapid growth. Teenagers need to eat well to help with growth spurts.
- Pregnant women have special needs. They need more food, since they must eat enough to support a steady weight gain: between 20 and 30 pounds before the baby is born.
- Pregnant women need extra protein and calcium. Sources include milk, fish, poultry, meat, eggs, cheese, and beans.
- Pregnant women need more iron. It is hard to get enough iron from food, so iron pills are usually needed.
- Pregnant women also need more folic acid. Folic acid is found in green leafy vegetables, kidney, liver, peanuts, and sometimes must be taken through pills.
- Pregnant women need to drink more fluid — at least eight to ten glasses of water daily, plus juices and milk.

A suggested diet for healthy mothers-to-be includes a quart of milk a day (or yogurt, cottage cheese), two eggs a day, two servings of leafy green vegetables a day, two or three slices of whole-wheat bread, and two servings of lean meat, fish, chicken, cheese, dried beans, or peas a day. In addition, pregnant women should eat some citrus fruits or juice, some whole grain cereals, some liver each week, baked potatoes, vitamin enriched butter or margarine, and the prescribed vitamins and pills listed above.

QUESTIONS

A Baby's Health Is Influenced By:

Whatever the mother takes into her body before and during pregnancy. This includes medicines, alcohol, tobacco, and other drugs.

Medicines

When pregnant women take medication without medical supervision, they may endanger their unborn children. Scientists used to think that a fetus was protected from harmful substances taken by the mother. They thought these would be screened out before they entered the fetal bloodstream. We now know that many substances can cross into the fetus. Even substances that may not harm the mother can be dangerous to the unborn baby.

These harmful effects have been discovered only after many babies were born with serious birth defects. Thousands of women in the fifties and sixties used the drug thalidomide while they were pregnant. Those who took the drug during the fifth week of pregnancy gave birth to children with deformed arms and legs. Thalidomide was given to help make pregnancy safer, but it was later found to damage the unborn child seriously if taken during one critical seven-day period. It took careful observation and testing over time to discover this.

Many substances have been found to be harmful as a result of the everyday observations of parents and those who work with parents and children. This was true in the case of the first substance known to produce cancer and to have crossed to the fetus through the *placenta* — the material that surrounds and nourishes the unborn child. Mothers of daughters who had a high increase of a rare type of cancer of the vagina were asked to be in a regional testing program. They talked among themselves while waiting to be examined, and found that they all had used DES, a synthetic estrogen prescribed widely to help prevent miscarriages. Their observations helped doctors and scientists pinpoint the drug's effects and warn against its continued use.

There is evidence, but no final proof, that other medications can cause birth defects when they are taken by pregnant women. Some are dangerous when taken in the very early stages of pregnancy, when the structures of the fetus are first forming. Others may be harmful in later pregnancy, when the bones are hardening. Some medications can be safe in small amounts but harmful in large or frequent doses.

Some medications under suspicion include:

- morphine and methadone
- antihistamines, taken for hay fever and other allergies
- some antibiotics, taken to combat infection
- aspirin or aspirin substitutes like Tylenol, when taken in large amounts
- products taken for indigestion like Bromo Seltzer and Alka Seltzer
- diet pills
- tranquilizers
- sleeping pills
- excessive amounts of vitamins A and/or D
- some ointments used for skin rashes

Ways You Can Protect Yourself Against Harmful Medications:

Stop the use of diet pills and sleeping pills. Take tranquilizers only under a doctor's supervision. Some tranquilizers have been known to cause birth defects. Women and girls who might be pregnant, even if it is not certain, should take no medicine without medical advice.

If you or a friend is pregnant, consult a doctor before using any medicines at all, especially ones bought without a prescription. The doctor supervising the pregnancy knows the patient's state of health, and can tell which medications are safe to use, in what amounts, and which ones to avoid.

Don't be afraid to ask questions about medications. Learn all you can about the impact of medications on the fetus and the mother.

John McGannon

Alcohol

Parents who are heavy drinkers run a very high risk of damaging their baby. Research has identified a very serious birth defect in new-born babies called FAS, or fetal alcohol syndrome. These babies are mentally retarded. They are deformed in the face and sometimes other places. They fail to grow normally, and they have heart defects. The mothers of these babies either drink a great deal regularly or go on binges of heavy drinking from time to time.

Studies that identified mothers who drink heavily have shown only a few of their babies with the full set of FAS symptoms. What probably happens is that an unborn baby suffers FAS only if its mother has been on a binge during a key period. The most critical time is the first three months of pregnancy.

The same studies of large numbers of pregnant women who drank heavily did show an increased number of other problems in their babies. Among these were low birth weight, jitteryness, and irritability. What will happen to these infants eventually is hard to say. It depends very much on the care they receive during childhood.

The children of alcoholics and heavy drinkers risk injury for other reasons. Heavy drinking is often associated with poor nutrition, heavy smoking, the use of other drugs, and with stress.

Alcoholic parents usually have other problems. Alcoholism in either parent usually interferes with employment, marriage, and other relationships. Alcoholic parents are less able to take good care of growing children.

Alcoholism And Teenagers

Recent studies of the drinking patterns of students in grades 7 through 12 have shown that drinking is increasing among teenagers. Drinking is also starting at an earlier age than ever before, and teenagers' drinking habits are becoming more like those of adults. The largest upswing in drinking is among teenage girls, who are now almost as likely as boys to be drinkers. A 1974 study of 14,000 teenagers showed 11 percent as "heavy drinkers," 16 percent as "frequent drinkers," and 14 percent as "moderate to heavy drinkers." Only about one teenager in four of those surveyed said they did not drink at all. Increased drinking among teenagers, plus a rising rate of teenage pregnancy, is disturbing. Adolescent drinking can be a real threat to the health of teenagers' children.

In a recent pilot program at Boston City Hospital, educational counseling and support services for alcoholic patients were part of a prenatal care program. Alcoholic parents were shown how their drinking could affect their unborn children. This information turned out to be a powerful motivating force to keep women in the program and to reduce their drinking. Some of the heavy drinkers reduced or stopped their drinking during the last three months of pregnancy. Others did not. The babies born

to all the mothers were examined after birth. Those born to women who reduced or gave up drinking showed fewer defects than those whose mothers continued to drink heavily.

This probably was the result of several things — not just the reduction in drinking. Women who slowed or stopped drinking also were active in all parts of the program. They received better medical care than the women who did not come in regularly, and they tended to follow medical advice in all areas of health care. The study shows that pregnant alcoholics are motivated to reduce drinking when they learn that the health of their unborn children is at stake. Such a program improves the outlook for the health of the children.

John McGannon

Tobacco

Babies born to mothers who smoke often are underweight and, therefore, get a poor start in life. These babies are more likely than others to die in their first month of life.

Carbon monoxide (CO) is a poisonous gas present in cigarette smoke. It is also found in car exhaust; but in the open air, where it is spread out quite a bit, it is less harmful than in the concentrated amounts present in cigarette smoke. When carbon monoxide is breathed into the lungs, it is absorbed by red blood cells, which carry it to the body tissues, just as they normally carry oxygen. Unfortunately, CO is useless to human cells. Because the red blood cells bring it instead of oxygen, the body cells are deprived of necessary substances. If their oxygen supply is cut off in this way for very long, they die. In small amounts, CO causes dizziness and headaches in children as well as adults.

In a pregnant woman, the effect is more serious. The baby's blood absorbs even more of the gas than her own. A mother's cigarette smoking will deprive an unborn child of needed oxygen and will result, in the long run, in slow development and lower birth weight.

The fetus also can be harmed by the nicotine in cigarettes. This chemical can make the blood vessels between the mother and the fetus grow narrow, which restricts the baby's food supply and further reduces the oxygen flow.

Studies have found that the umbilical cord, which carries all necessary materials to the baby, is sometimes damaged in mothers who smoke. No one is sure just what causes this damage.

Although unborn babies do not exactly breathe, they do "practice" breathing before birth by exercising muscles they will use when they are in real air. When a mother smokes, she reduces these movements — even after only two cigarettes.

Other Drugs

When parents are addicted to hard drugs like heroin and methadone, they are running a very high risk of seriously damaging their unborn children. When parents or future parents use any drug heavily, they run risks, although the exact effects are not yet known.

Between half and three-fourths of the babies born to women who are hard drug addicts are themselves addicted and show withdrawal symptoms after birth. Newborn babies with withdrawal symptoms are in serious trouble. If not treated promptly, they may die.

Women who are hard drug addicts are more likely to have difficult pregnancies. Complications may be caused by the drugs themselves, or by lifestyles and habits that the drugs make necessary or likely.

Studies show that women addicts usually do not seek or get good prenatal care. In many cases, the pregnant addict has had no care at all until labor starts. Babies born to addicted women are more likely to be born prematurely, and they often weigh less than babies born to women who do not use drugs

Most teenagers who use drugs regularly do not consider themselves addicts. They are not physically addicted to hard drugs, but use drugs either regularly or in heavy amounts. Heavy amphetamine use ("speed, uppers") is known to cause permanent brain damage to the user, and probably to the unborn children of mothers who are heavy users. It is also known to deplete calcium, which is needed for the unborn baby. Hallucinogens (LSD and other "acids") may produce long-range chromosomal changes, although the exact effects are not yet known. The use of "downers," amyl nitrate ("poppers"), STP ("angel dust"), cocaine, glue, and similar substances — some legal and some illegal — can have serious consequences for mother and unborn child alike. While the evidence for the effects of hashish and marijuana is not clear, heavy use of any artificial substance, and certainly any substance that produces immediate mind-altering affects, should be avoided by pregnant women and girls.

Parents who are addicts or heavy users of any drug are less likely to be able to take good care of children. They must deal with many problems, and they sometimes are disoriented. The stress of caring for a baby, especially one with problems, may be more than they can undertake.

Special treatment programs for pregnant addicts have been set up in some hospitals. Many addicted mothers who join prenatal care programs and receive both medical help and counseling have been able to reduce or end their dependence on drugs. One doctor in such a program described what she found:

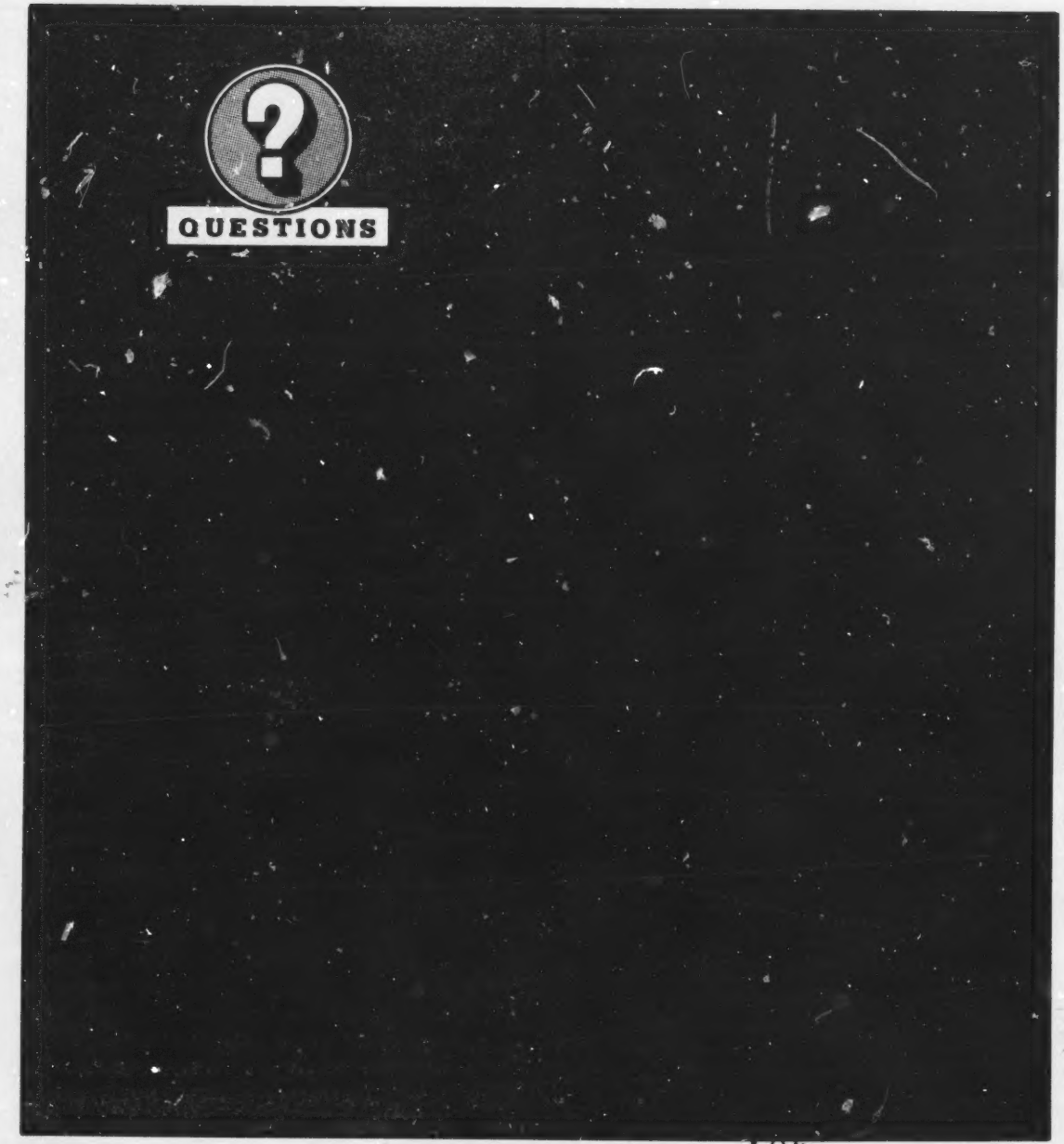
> *It was easy to reduce the dose of methadone in pregnant addicts, who were extremely motivated by the fact that their unborn infant may be subject to untoward [terrible] effects because of the prenatal stress of maternal drug usage.*

A Baby's Health Is Influenced By:

The environment in which the family lives.

Today, expectant mothers — and the babies inside them — are exposed more often to more substances that may harm them. Two reasons for this change are: the increase in products that use artificial materials and ingredients; and the increased tendency to work outside the home and in a greater variety of jobs.

This does not mean that we should become paralyzed with fear, or confine expectant mothers to the house and restrict their diet to all natural foods. But we can learn as much as possible about the products we are exposed to, and use common sense about contact with them. We can keep an eye out for health problems in ourselves, our families, and our communities. Finally, we can support research to test the materials in products before they are used. Right now we are at the frontier of research in this area. Many things that we need and use will prove harmless, but some will be shown to cause birth defects or other serious problems for us and for our children. The facts are not all in, and much of the available information is confusing. Time and money for research and testing are necessary.



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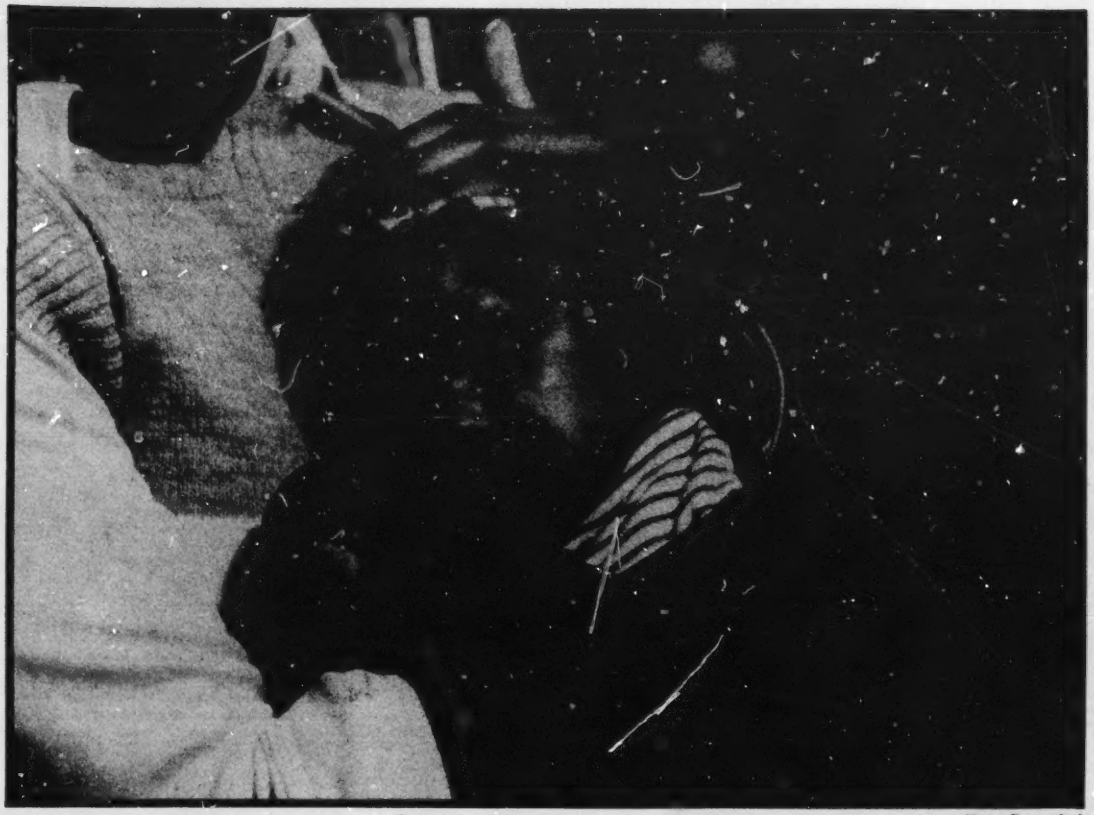
This information was compiled from the following sources: "Occupational Health Problems of Pregnant Women," by Vilma Hunt, *A Report and Recommendations for the Office of the Secretary,* Department of Health, Education and Welfare, April 30, 1975, #SA 530475; "Working for Your Life: A Woman's Guide to Job Health Hazards," by Andrea Hricko with Melanie Brunt, Labor Occupational Health Program and Public Citizen's Health Research Group, 1976; *Occupational Health and Safety Symposia,* Department of Health, Education and Welfare Public Health Service, HEW Publication Number (NIOSH) 76-136.



Karin Rosenthal

A Baby's Health Is Influenced By:

Family income — how much money the parents have during pregnancy and after birth, and whether they live in an environment of poverty.

One factor that has a great influence on a baby's health before and after birth is money: how much of it the baby's family has, and how much can be used wisely for the baby's health. Income has a great deal to do with the kinds of work parents do and the hazards they may face on the job. Lack of money often means lack of good food and good prenatal care. Children whose parents live in poverty are more likely to be unhealthy at birth than those born in better circumstances. What's more, the problems at birth are likely to grow worse if the children are raised in poverty.

If the parents live in a community that is poor, the services they need to stay healthy may simply not be around. If the people around the baby and mother are also poor, they may have had no contact with good medical service and may know little about the needs and care of babies before and after birth. Poor people often live in unhealthy surroundings, which may further endanger the baby and the mother. There also are families who are poor, who live in a healthy atmosphere, and who know about good health and how to get what they need. But most poor people don't have these advantages, and their babies suffer.

Prenatal Care

Mothers who face the most serious risks during pregnancy are those who receive the least prenatal care and get it late. A study of 130,000 live births in upstate New York in 1973 showed that three out of four women who were not poor, not uneducated, and who did not have problems in previous pregnancies, did get prenatal care in the first three months of pregnancy. Less than half of the women who faced these risks had received early care.

According to public health data, about 600,000 women in the United States are living in poverty. Public prenatal care programs only reach about half of these women. That means many expectant mothers are probably without care. The situation gets worse in hard times. A study of the infant death rate and the economy over the last 45 years showed that more babies die when unemployment is high.

Where you live is important. Even if you are poor, you often can get good care if you happen to live in a wealthy community. Most poor people live in neighborhoods that are poor, in rural areas where services are far away, or in cities so large or crowded that public services are overwhelmed. If medical care for all pregnant women in New York City met public standards, for instance, the infant death rate there could be cut by one-third.

Sweden, which has almost no poverty, has provided prenatal care to all mothers and reduced the infant death rate to the lowest in the world. Average birth weight has increased and the health of pregnant women and their babies has improved.

Nutrition

A study of autopsy findings in all stillbirths during one period in a city compared infants whose families lived in poverty with infants from other families. The poor infants weighed less. These are some of the signs of malnutrition. Another study linked poor diet with poor housing. A mother living without a stove, refrigerator, or indoor running water will have a hard time feeding her children well, no matter how much she knows about nutrition.

As mentioned above, it is hard to buy enough good food when you have little money. Food prices have been the first to go up over the last few years. Especially in cities where people have to shop in food chains or expensive corner stores, food costs a lot. Studies have shown that the quality of foods available in poverty areas is much lower than in other neighborhoods. Finally, poor people may know little about nutrition or about good food budgets and planning, because they have less access to this information. They may end up wasting money on junk foods, foods from fast-food restaurants, and fad foods pushed on TV.

AUTOPSY: study of bodies to find cause of death.

Low Birth Weight

Statistics show that a baby who weighs 7.5 pounds or more at birth has the best chance for a healthy start in life. Doctors think that 5.5 pounds is the dividing line between low and full birth weight. They are concerned about low birth weight, because half of all infant deaths in this country are linked directly or indirectly to this problem.

Many factors determine a baby's development and weight; often we cannot be sure why some babies weigh less at birth than others. Sometimes babies don't stay inside the mother for the full nine-month term. These babies, born prematurely, often weigh less than full-term babies. But even full-term babies are subject to low birth weight.

We don't know why low weight babies are more susceptible to health problems, but babies who weigh less than 5.5 pounds at birth are more likely than full-weight babies to:

- be injured during birth
- require special medical attention in the first weeks of life
- have circulatory and respiratory problems
- have physical and mental handicaps
- die from birth defects
- have health problems throughout life
- develop learning problems in school

The less a baby weighs, the more these problems are likely to occur.

Low birth weight and premature babies are born more often to mothers who:

- try to lose weight during pregnancy
- smoke
- drink excessively
- take other drugs
- are undernourished or suffer from malnutrition
- are 15 years old or younger
- fail to get prenatal care

A mother will want to do all she can to have a baby that weighs more than 5.5 pounds by

- eating a complete and well-balanced diet
- being careful about alcohol, cigarettes, and drugs
- getting good care from her doctor from the start of her pregnancy

Many babies with low birth weights do well in spite of the increased danger. Today good medical care, the use of new nursery equipment, and special attention from parents can help the low-weight baby do well.

Advice to pregnant women has changed and keeps changing. Your mother probably was advised differently than a mother would be today. When you were born, most doctors were very strict about how much weight they would allow their patients to gain. Women who did not gain a lot of weight were considered better patients. Today, doctors think a weight gain of 20 to 30 pounds is about right. A woman whose weight gain falls within this range will help to give her baby a good start in life.

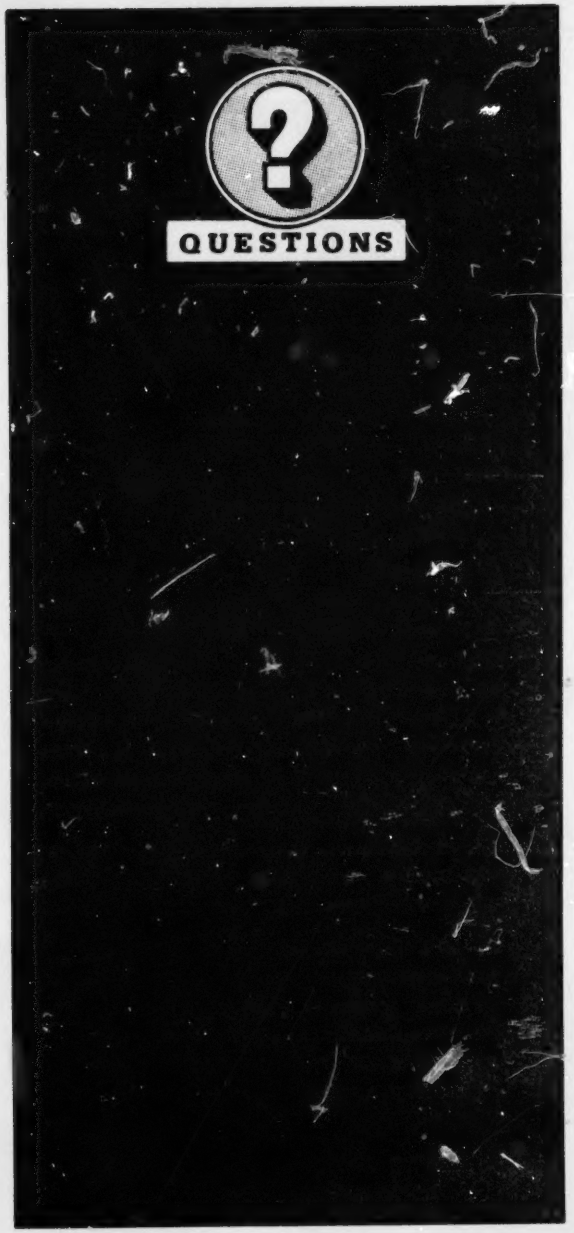
Mental Retardation And Poverty

Three-fourths of the retarded children in the United States live in rural and city slums. A child from a low-income family living in such an area is 15 times more likely to be retarded than a child from a family with higher income.

Most people are not poor by choice. They cannot be blamed for the risks their children face. But parents who are poor can cope with their difficulties and give birth to healthy children. It is a hard pull, however, and an unfair struggle for parents and children alike.

Parents who live in poverty obviously have a harder time getting the things their children need. They have to manage on a very tight food budget, yet they have to give their children a good diet. They may have to learn complicated rules to get government help, like food stamps. They have to look hard for cheap or free prenatal care and later for day care. Sometimes the places they turn to are hard to reach, crowded, and even unfriendly. People without money have to endure a lot. They have to fall back on their own know-how at times, and at other times they have to move mountains to get special care and expert advice.

One obvious and necessary solution to all of this is to end poverty. We can work as individuals to help society do that, and we can help poor people find jobs, education, and needed services. The answer for individuals as well as society is to remember how valuable every human being is, and how important the job of parenting is. People can cope, and they can get help, if they know they are worthwhile and if they can get the information they need to make the right decisions.



A Baby's Health Is Influenced By:

The age of the parents.

Teenage parents run a high risk of having children with health problems and birth defects. The mothers also run risks. The younger the parents, the greater the risks.

- Infant death: About 6 percent of babies born to mothers under the age of 15 die in their first year. This death rate is 2.5 times higher than for babies whose mothers are in their twenties.
- Pregnancy complications: Teenaged mothers are more likely than older mothers to have health problems during pregnancy, and to have trouble with labor and childbirth. There is a higher death rate for teenaged mothers than for older mothers. Their babies are twice as likely to have birth defects.
- Low birth weight: Sixteen percent of babies with birth defects weigh less than 5.5 pounds at birth. Twice as many babies with low birth weight are born to mothers under 15 than to mothers in their twenties. The rate of low-weight babies born to mothers in their late teens is also higher than for mothers in their twenties. Low birth weight sometimes causes babies to die. Most low-weight babies survive, but they are more likely to be sickly or have birth defects.

Young parents face many risks, and it is especially hard for them to cope with pregnancy and raising children. In our society, teenagers are under special stress. They are expected to act like adults, and they are taking up adult habits at earlier ages. Yet teenagers still lack the respect given to adults, and they find it difficult to live on their own. It is harder for teenagers to find decent jobs and to find places to live. The unemployment rate for all people has been high in the United States lately (between 6 and 15 percent, depending on where you live and what your race is). For teenagers seeking work, the unemployment rate is much worse: depending on sex, race, and section of the country, it ranges from 15 to 80 percent!

Teenage girls may not eat well because they worry about getting fat or about not fitting into the latest styles. They often feel they must hide the fact that they are pregnant, especially from their parents, from the father of the child, or from people at school or work. If they are worried, their emotional state may affect their health, and they may put off getting any medical care.

A pregnant teenager may have to drop out of school and do other things that make life harder and less pleasant. After the child is born, she will face more problems: how to work and raise a child; how to go back to school if possible; how to find cheap day care. She may

Susan Wing

need to go on welfare even if her family is not poor, and she will soon find that the money she gets is very limited. In other words, she will have to face all the hassles that poor parents face.

Teenage fathers also find it hard to be good parents and to give the mother and child the emotional and financial support they need. If the father has to drop out of school, jobs will be even harder to find. Plans for the future may have to be abandoned. It's hard not to feel resentment when this happens. These pressures are just too much for many teenage fathers. They may try to avoid helping the mother at all, during pregnancy or after birth. Others offer what help they can outside marriage, but often that help is very limited. Even when a teenage couple gets married, the chances that the marriage will last are not good: nearly half of the marriages of couples between the ages of 15 and 19 end in divorce, far more than marriages among older people.

Couples who marry before they're ready, and mothers who have children they don't want or aren't ready for, often take out their aggressions on children. This is called child abuse. It's ugly, it's widespread and spreading, and it can happen to the best of people. Teenage parents are often under the kinds of stress that lead to child abuse.

Dealing With Teenage Pregnancy

Faced with these problems, girls who think they are pregnant, and boys whose girlfriends have just told them they are pregnant, often run away. Counselors of runaways say that pregnancy is one of the main causes of running away, and that it usually makes things worse for the people involved. If you know any runaways or anyone who is thinking about it, they can get completely confidential help by calling the National Runaway Switchboard, 1-800-621-4000.

Young parents can cope. They can get help from their own parents more often than they realize, and from other relatives and neighbors as well as doctors and school counselors. In most communities there are hot lines and centers for teenagers that give information with no questions asked. These centers often provide a number of services. If you can't find out about these places locally, look in the *People's Yellow Pages,* available in many bookstores, or write for the National Hotline and Crisis Center Directory, National Exchange, 311 Cedar Avenue South, Minneapolis, Minnesota 55404.

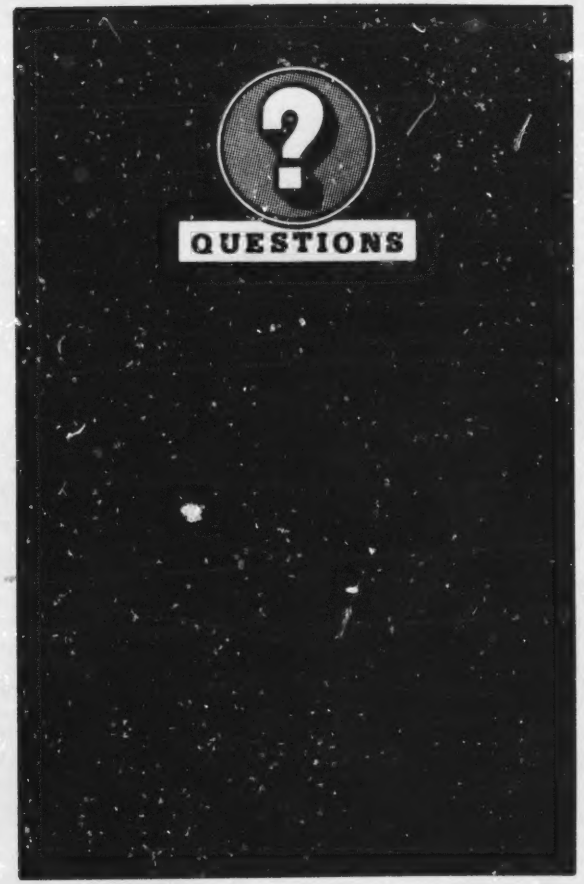
The Big Decision

It's really nice to have children and to learn how to be loving mothers and fathers. You will want to give your children the best possible start by helping them to avoid all the problems you've just read about. You need to be ready for the experience. The world you face needs to be as helpful and comfortable as possible. That usually is not the case for teenagers who are about to become parents.

Besides, it is also very nice to be 17, 18, 19, even 20, and not have children, not be tied down. You may want to bum around awhile, work for a cause that is important to you, or work at a beach or ski resort. You may want to study art or music or carpentry. Whatever you want, it will be harder to do if you have responsibilities to a wife or husband and to children. Being on your own and without children lets you move around more, and it improves your chances for moving up and getting ahead.

Generally speaking, young women under the age of 19 just shouldn't have children. Every one of the problems listed can happen to anyone, but they are more likely to happen to teenagers. The teenagers suffer, and their children suffer even more.

But the choice is yours; for you, starting a family at a young age may be just the right thing. If you or a teenage friend decides to have a baby — or if things get beyond choice, and you or they think pregnancy is likely — then there are things to be done to reduce the risks. In such cases, teenagers who smoke, drink, take drugs, or have a history of health problems or birth defects in the family should get information and help before having children. Pregnancy is no cause for panic, but it is a serious and complicated business, especially for teenagers. It calls for careful consideration and planning, and for good professional advice and medical care.



ACTIVITY
Helping Yourself And Others

Jerry Howard

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Glossary

A glossary defines words you may not know that are important to understand. Reading straight through it may give you some new information about birth defects and other subjects important to the health of parents, children, and teenagers.

Addict A person who must have a substance, usually harmful, for daily life. Addiction usually means there is a physical dependency (need), as in alcohol, heroin, etc. There are also psychological or emotional addictions, in which the substance is used as a crutch but is not physically addictive. Ending the use of an addictive substance will cause craving (strong desire similar to hunger or thirst) and other withdrawal symptoms such as pains, aches, nausea, vomiting, cramps.

People may use a substance, like alcohol or heroin, and not be addicts. Heavy use of a substance is often as serious as addiction, however. When a pregnant mother is addicted to a substance like heroin, the baby may be born an addict and go through withdrawal. Heavy use of both heroin and alcohol can cause serious birth defects.

Alcoholism Addiction to alcohol. Help is available through groups like Alcoholics Anonymous, ALANON, and ALATEEN, and is absolutely necessary for pregnant women who drink a lot or are alcoholics.

Anesthesia Loss of sensation that may be caused by certain drugs called anesthetics that are usually given before an operation or sometimes during a difficult birth.

Brain Damage Injury to the brain may occur during pregnancy, at birth, during infancy, or later, sometimes resulting in retardation, disorders of the nervous system, such as cerebral palsy and epilepsy, or physical disabilities.

Cartilage White, semi-opaque tissue found in all human beings. Also called gristle. In infants, most cartilage begins to form into bone, a process that continues for many years of growth.

Cerebral Palsy (CP) Disorder of the nervous system characterized by disturbances of motor function. This means the person has difficulty controlling his/her movements. Cerebral palsy usually occurs at birth, but damage or injury to the brain that occurs at any time in life can cause the disability. Commonly, a person with CP may have difficulties with balance, speech, spasms, and limb movement. Some people need crutches or wheelchairs while others can walk and move about independently. Intelligence ranges from above-average to severely retarded.

Chromosome The threadlike material in humans and other animals that carries the genes into the core or nucleus of cells in order to pass on inherited traits or characteristics from the parents to the children. Chromosomes can be seen only under a powerful microscope. There are 23 pairs of chromosomes in each fertilized egg. Every time a new cell is produced, the chromosomes make copies of themselves.

Cleft Palate and Cleft Lip A birth defect that keeps two sides of the lip or the palate (roof of the mouth) from joining together. About 4,300 children are born each year with this problem, which can usually be corrected by surgery. It can be inherited and/or caused by conditions during pregnancy or at birth.

Club Foot A foot that is deformed before or at birth. Like cleft palate and cleft lip it can be inherited and/or caused by influences during pregnancy or at birth. This deformity and others like it can be corrected. Unfortunately many families do not know this, or cannot pay for the surgery, or are afraid or unwilling to have the operation performed.

Colic Many healthy babies get this condition during the first few months. Symptoms include constant crying, gas, and stomach pains. It goes away as the baby grows. It may be caused by rapid growth or by the sudden change from the womb to the outside world. Colic is seldom serious, but it takes much time and energy from the parents.

Conception The sperm from the man fertilizes the woman's egg during intercourse.

Convulsion Sudden jerking or spasms (involuntary muscle contractions) with possible loss of consciousness (fainting) and temporary halt to breathing. Convulsions may be a sign of brain damage in infants. Convulsions also happen with very high fever. They may or may not be serious.

Cystic Fibrosis This disease, which is inherited, affects the mucus glands. It causes a thick fluid to develop in the lungs and intestines, making it difficult to breathe or digest food. About one out of every 2,000 babies has it—it is one of the most common inherited diseases among Northern Europeans. Those who have it may live into their twenties, with medical help. There is no known cure.

Depression A feeling of being down, unhappy, lacking energy, angry at self, apathetic toward self and others. Extreme and lasting depression becomes an illness that is often unrecognized and untreated, although there have been recent developments in treatment through vitamins and diet as well as drugs. Little is known about the many different forms of depression; some may be caused physically or may be inherited, while others may be caused by problems in life or work. Almost everyone suffers short, mild depression. Depression may occur at certain points in life, such as menopause in women, and right after giving birth (which is called postpartum depression).

DES A medicine that was once prescribed to help women avoid miscarriages or spontaneous abortions, and as a "morning after" birth control pill. Daughters born to women treated with DES may get cancer and sons may become sterile. It is also used to fatten cattle.

Developmental Disabilities Children with developmental disabilities are children with mental retardation, cerebral palsy, epilepsy, or combinations of these or related disabilities.

Diabetes An inherited disease affecting the body's ability to break down and convert sugar and starches to energy to be used by the cells. Diabetes may become evident in childhood, but more often symptoms appear in middle age. Usually diabetes can be controlled by medicine and diet. Diabetic women under good supervision can have healthy babies. Symptoms include craving sweets, sweating, cold or itching hands and feet, problems with seeing and/or urinating, nervousness, extreme tiredness. Although it is easy to control and very common, diabetes is a good example of an inherited disease that causes real problems for those who have it and their families. There are daily shots or medicines, special foods to be eaten or avoided, and instructions for emergencies when medicine is not taken or too much or too little sugar is consumed. Diabetics must use artificial sweeteners. Many are fighting the proposed ban on saccharin, which is said to be a possible cause of cancer, because life without it would be even more complicated. Researchers are working on developing other artificial sweeteners to replace saccharin.

Dominant Trait A characteristic that will pass on to the children if either parent has that gene.

Down's Syndrome A chromosomal disorder resulting in extra chromosome material that causes an irregular structure of genes. This disorder is characterized by facial and physical abnormalities such as slanting eyes that are far apart, small ears, a flattened nose, and shorter than average hands, feet, neck, torso, arms, and legs. Individuals with Down's Syndrome are mentally retarded, the degree of retardation usually ranging from moderate to severe. This disorder is more likely to occur in children born to mothers who are over 35 or under 17.

DNA An organic acid in all species of creatures that causes inheritance by creating and reproducing genes and chromosomes.

Edema A swelling that happens when fluid is collected in body tissues. In a pregnant woman, it is a symptom of a very serious condition called toxemia.

Embryo The word for an unborn child from a time shortly after conception to about the end of the third month.

Environment The setting or conditions in which something exists; the world in which we live. The environment of pregnancy, for instance, includes the lifestyle of the mother, her nutrition and general health, as well as the products and emotions to which she is exposed and the social and economic conditions of her family and community. It is often contrasted with heredity.

Epilepsy A disorder of the control of impulses of the central nervous system, characterized by convulsive seizures, loss of consciousness, and disturbance of the sensory and motor systems. Epilepsy may (but does not always) accompany brain damage, and sometimes it is complicated by retardation. It is treatable with anti-convulsant drugs.

Fallopian Tubes (oviducts) A pair of slender tubes in the female that form canals from the ovaries to the uterus. The egg, when released from the ovary, passes into one of these tubes; if sperm are present, fertilization usually occurs here. Otherwise the egg passes through the uterus to the vagina and out of the body.

Fetus The unborn child from the end of the third month of pregnancy until birth.

Gargoylism A congenital abnormality characterized chiefly by grotesque deformities of the head, trunk, and limbs, dwarfism, mental retardation, and enlargement of the liver and spleen. Deafness, joint contractures, and cardiovascular defects are also characteristic of gargoylism. A recessive trait, it is also known as "Hurler's Syndrome."

Gene A small particle (made of carbon, hydrogen, oxygen, nitrogen, and phosphorous) that contains one trait or characteristic from a parent. The genes are arranged in various ways along the 23 chromosomes. A gene may carry the message to make a protein, to make skin, etc. This information directs the cells to become various parts of the body. How they are arranged in the chromosomes determines whether we have brown or blue eyes, freckles, birth defects, tongues that curl, and all our other physical traits.

German Measles See Rubella.

Gonorrhea See Venereal Disease.

Gynecologist A doctor who specializes in the female reproductive system.

Hemophilia An hereditary disease caused by a recessive trait passed from the mother usually only to sons. It is characterized by an extremely slow rate of clotting and can result in severe bleeding from the smallest scratches. Although it is painful and dangerous, it can be controlled by injection and transfusion. The occurrence of hemophilia in a number of royal families in Europe, including the Romanoffs and the Bourbons, has been traced back to Queen Victoria of England as the primary source of this gene among royalty.

Heredity (inheritance) The physical and other traits or characteristics that are passed from parents to their children. They may be modified by environment. It is important to remember that most defects and diseases, as well as other traits, are caused by a combination of heredity and environment.

Herpes Simplex See Venereal Disease.

Huntington's Disease An inherited disease caused by a dominant trait. The symptoms usually do not show up until age 30 or older. It causes the brain and nervous system to deteriorate slowly, and affects movement and speech. It is sometimes mistaken for drunkenness. The musician Woodie Guthrie died of it, as the movie *Bound for Glory* showed.

Hyperactivity A term used to describe several conditions and symptoms, especially in children. Hyperactive children are jittery and constantly moving. There is some evidence that hyperactivity may be caused by lead poisoning and by some of the preservatives and other substances in various "junk" foods. Some doctors claim to have reduced or eliminated it through diet. Other hyperactive children are treated with drugs. Some people argue that hyperactivity in children should be acceptable, and that the primary problem is the negative attitude of adults toward children with this characteristic.

Incubator An artificial environment prepared for premature babies to help them survive. An incubator imitates some of the conditions of the womb.

Infantile Autism A developmental disturbance reflecting the inability to relate appropriately to self, objects, and people. Functional retardation occurs, with many accompanying disturbances of behavior and communication.

Low Birth Weight Average birth weight is about seven pounds, five ounces. Less than five pounds is considered low birth weight. Many babies, but not all, who weigh less than 5.5 pounds are premature—born sooner than nine months. Low-weight babies have high risks. The risk of death is 17 times higher than for full-weight babies. They suffer more often from CP, epilepsy, mental retardation, deafness, blindness, deformities, and other problems. Low birth weight is often associated with poverty, poor nutrition, and poor prenatal care.

Mainstreaming A word used in some states to indicate that special-needs children are educated in classes with normal children.

Malignant Cancerous. A tumor or substance that is malignant contains and/or causes cancer.

Malnutrition Lack of the right foods to the point that the person is harmed physically or emotionally. Malnutrition may cause temporary or permanent brain damage and other problems in the unborn, infants, children, and adults. It is usually, but not always, associated with poverty.

Maternal Having to do with the mother. Maternity has to do with a pregnant woman: maternity clothes, maternity death rate, etc.

Menopause The time, usually between the ages of 45 and 55, when women stop menstruating.

Menstruation The discharge of blood and mucus from the uterus that usually occurs in sexually mature females in cycles of about a month each. Menstrual means anything connected with menstruation.

Mental Retardation Mental retardation covers a wide variety of disabilities. The retarded person does not learn at a normal rate and has problems in adapting to what society expects. In addition, mentally retarded individuals often have other disabilities such as motor functioning, sensory handicaps, speech problems, and emotional and personality disturbances. There are four recognized levels of retardation: mild, moderate, severe, and profound.

What this means is that the retarded person may be totally independent, require total care or fall anywhere in between. For example, moderately retarded people require special education, usually vocational training to learn to work at simple tasks, and have the capacity to live happily and comfortably in a protected environment. Generally, the profoundly retarded individual is severely handicapped both physically and mentally, and requires constant attention and care.

About 126,000 mentally retarded babies are born each year in the United States. Some principal factors causing development defects are genetic, fetal disturbances during pregnancy, infectious, toxic, and nutritional difficulties during and after the birth period.

Miscarriage Also called spontaneous abortion, the death of a child born prematurely, without outside interference. When this is done with outside interference, it is called abortion.

Mongolism, Mongoloid See Down's Syndrome.

Muscular Dystrophy (MD) Several inherited diseases in which the muscles attached to the bones grow weaker and weaker, causing difficulties in movement and also causing deformity.

Neurologist A doctor specializing in finding and treating diseases and defects of the brain and central nervous system.

Obstetrician A doctor specializing in the care of pregnant women and in delivering babies.

Orthopedist A doctor who specializes in treating the spine, bones, joints, muscles, or any other parts of the skeletal system.

Ovulation The release of an egg (ovum) from the ovary (reproductive organ) of a female, which

occurs in most females about 14 days before menstruation.

Pediatrician A doctor who specializes in treating children.

Phenylketonuria (PKU) This inherited defect causes the body to be unable to breakdown or metabolize amino acids in meat, fish, eggs, cheese, and milk. It is a recessive trait caused by the lack of one enzyme, a substance necessary to digestion. It can lead to mental retardation, but diet and medical care begun at birth can result in a healthy child.

Physical Therapist A professional health care person who treats diseases and defects with heat, massage, or exercises.

Placenta The material surrounding the fetus that nourishes it, disposes of its wastes, and both connects and separates it from the mother.

Pregnancy The time between conception and birth, which usually takes about nine months. Certain symptoms may indicate that there are problems with the fetus:

- bleeding from vagina
- severe, continued nausea and vomiting (some of this is normal)
- continued, severe headaches
- swelling or puffiness of face, hands, feet, or ankles (not to be confused with normal weight gain in pregnancy)
- blurred vision, spots before the eyes
- marked decrease in amount of urine
- pain, burning in urinating
- chills and fever
- sharp, continuous abdominal (stomach) pains
- sudden gush of water from the vagina before the baby is due.

Premature See Low Birth Weight.

Prenatal Care Careful supervision by doctors, nurses, or midwives of the pregnant woman and unborn child. Over 25 percent of all women in America do not begin prenatal care until after the third month or do not have it at all. This increases the risk of death to child and mother, and of low birth weight, pregnancy complications, prematurity, and birth defects.

Recessive Trait A characteristic in a person that will pass on to the children only if the gene is passed on by both parents.

Rh Factor This is one of the factors in our blood. Most people have it, and their blood is called Rh positive. About 20 percent do not have it, and their blood is called Rh negative. This has no effect on the individual. It becomes important when a woman who is Rh negative is pregnant from a father with Rh positive blood. Their baby may die or have serious problems because the mother develops harmful substances in her blood. Any woman with Rh negative blood should remain aware of this and, when pregnant, receive the proper care to prevent the problems. She can also receive a vaccine three days after having a baby or an abortion. The vaccine can prevent the harmful substance from building up in her blood to threaten the health of any future babies.

Rubella Also called German Measles, this is a mild, contagious disease (not inherited) that lasts only a few days and causes a sore throat, fever, and rash. The baby of a pregnant woman with rubella can develop birth defects such as deafness, heart defects, eye diseases, damage to the central nervous system, and mental retardation. There is a vaccine that can make you immune to rubella, but it should not be given to anyone who is or might be pregnant. It should be given to all children before puberty. It prevents the spread of rubella by immunizing young girls and by keeping children from giving it to pregnant women. Girls and women who may be pregnant can and should be tested to see if they have rubella.

Sickle Cell Anemia An inherited disease, especially but not only among black people. About one in every 400 black children in America has it. It causes extreme tiredness, poor muscle tone, nausea, and sometimes early death. It is caused by an abnormality in the red blood cells, and it is a recessive trait. It can and should be detected and treated in children, adolescents, and adults. At present, however, there is no known cure for the disease. People who are carriers of the sickle cell trait may or may not have the disease themselves.

Species A basic biological unit identifying related animals or vegetables: human beings, dogs, and cats, for example. Ordinarily, reproduction can only occur within a species, not across species.

Spina Bifida A birth defect caused by heredity and environment. The infant's spinal canal is not formed properly. The defect varies in seriousness but can cause crippling and mental retardation. It can sometimes be detected before birth. About 6,200 children are born yearly with this defect.

Spontaneous Abortion See Miscarriage.

Stethoscope An instrument that enables a doctor to study sounds in the body. For example, a stethoscope allows a doctor to listen to the heartbeat of a baby before birth.

Syndrome A group of symptoms that, when taken together, usually characterize a disease. Syndromes are usually named after the scientist who discovers or first describes them: for example, Down's Syndrome.

Syphilis See STD.

Sexually Transmitted Disease (STD) Several diseases, including gonorrhea, herpes simplex II, and syphilis that are very infectious. They are spread by sexual and sometimes other intimate contact. Symptoms vary, but include pain or difficulty in urinating; sores and lesions near or on sexual organs, the mouth, nose, ears, or fingers; slight fever and persistent sore throat. Especially in women, there may be no recognizable symptoms in the early stages. All of these diseases can be detected, and all persons engaging in sex should be checked.

Treatment for syphilis and gonorrhea is simple and often free; these two diseases can usually be cured promptly. The tests and treatment can be had easily and in confidence. Yet these diseases are spreading rapidly, especially among teenagers. If untreated, they can lead to sterility, mental illness, blindness, and death.

Herpes simplex II is also becoming widespread. At present there is no known cure. The infection usually lasts about 10 to 14 days, and is charac-

terized by painful blisters. Half the infected babies die; half the survivors are physically or mentally impaired.

If you suspect that you have any of these diseases, it is important to get medical care immediately.

Tay-Sachs Disease This inherited disease is very rare, but always causes death. It usually appears shortly after birth, but may not emerge until age five or later. The child's eyes are marked with a red spot, and there is increased blindness and weight loss. It is recessive, and 85 percent of the cases are Jewish couples with ancestry in Eastern Europe.

Thalessemia Also known as Cooley's Anemia, this is an inherited disease caused by a blood abnormality. Those who inherit it from both parents need constant blood transfusions and usually die before age 20. Those who just carry the trait are only slightly affected.

Thalidomide This drug used to be prescribed to pregnant women to help them sleep or be calm. It produced severe deformities in the babies of these mothers. Because the U.S. Food and Drug Administration refused to allow it, thalidomide was never used in this country.

Therapy Treatment for any physical, mental, or emotional problem.

Toxemia A disease during pregnancy with symptoms that include high blood pressure, extremely heavy weight gain and unusual swelling, and, in extreme cases, convulsions and coma. Toxemia is thought to be caused by improper diet, and it can be corrected with proper care. If untreated, it can cause the death of the mother and the unborn child, or birth defects. Sometimes, pregnant women confuse weight gain with toxemia. Some weight gain and swelling is normal and desirable in pregnancy; the bloating caused by toxemia is clearly different and more serious.

Trait A characteristic. See Dominant and Recessive Traits.

Trimester A period of three months. Pregnancy is usually divided into three trimesters.

Uterus The womb; the place in the mother's body where the fetus grows and develops before birth.

Venereal Disease (see STD)

Womb (see Uterus)

Zygote The egg, after it is fertilized by the sperm.